Developing Policy Guidelines to Promote the Quality of Life of Young Adults with Perinatally Acquired HIV in Botswana.

by

Grace Karugaba

Submitted in accordance with the requirements for

the degree of

Doctor of Literature and Philosophy

In the subject

Health Studies

at the

University of South Africa

Supervisor: Prof. Gloria Thupayagale-Tshweneagae

February 2020

Student number: 3274-340-8

DECLARATION

I declare that this thesis: Developing Policy Guidelines to Promote the HRQOL of Young Adults with Perinatally Acquired HIV in Botswana, is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

DEDICATION

I dedicate this work to my father Stephen Karugaba Atwooki, my best teacher, and my greatest morale booster who anchored my hope in education. To my mother Naomi Karugaba Abwooli for her unfailing love. To my siblings and their families for the wonderful company. And to all those who love and care for young adults living with perinatally acquired HIV/AIDS.

ACKNOWLEDGEMENT

I wish to acknowledge the undermentioned for the support and guidance I received in undertaking this study.

The management of Botswana-Baylor Children's Clinical Centre of Excellence for permitting me to conduct the study. Special gratitude to all staff, interns and volunteers at Botswana-Baylor Children's Clinical Centre of Excellence for all the support they provided in the process of data collection.

My special appreciation to my supervisor Professor Gloria Thupayagale-Tshweneagae for the research competencies she imparted to me. I thank her for her technical guidance on the study and particularly in report writing.

I would like to express my sincere gratitude to all the young adults who participated in this study. I thank them for generously sharing their lived experiences and insights on how their Health Related Quality of Life could be enhanced. I also thank them for their positive energy, perseverance and love despite the challenges they are faced with.

Abstract

Due to the successful rollout of the Antiretroviral Therapy Program, an increasing number of perinatally HIV infected adolescents are emerging into young adulthood throughout Botswana. Young adulthood is a critical period of human development, with long-lasting implications for a person's economic security, health and well-being. During this time, young women and men normally complete school, find employment and start working, develop relationships, form families, bear children and pursue those things that help set them on the path to healthy and productive adult life. However, the presence of a chronic illness such as HIV can interfere with the achievement of the developmental milestones of young adulthood and affect their Health Related Quality of Life (HRQOL). The purpose of this study was to identify the factors that affected the HRQOL of young adults living with perinatally acquired HIV (YALPH) and to propose policy guidelines to promote their HRQOL.

A mixed-methods sequential explanatory research design was used. HRQOL assessments were made using the WHOQOL-HIV BREF instrument. Data about the clinical characteristics of the respondents was obtained from medical records. In-depth interviews were conducted with a purposefully selected subsample of respondents who completed the WHOQOL-HIV BREF instrument. All the respondents were recruited from Botswana-Baylor Children's Clinical Centre of Excellence, in Gaborone, Botswana. Data were analyzed using SPSS Inc. software version 16.0 (statistical package for social science, SPSS Inc, Chicago, IL, USA).

The study population consisted of 509 YALPH including 255 (50.1%) females and 254 (49.9%) males. The mean age of the population was 21.7 (± 2.6) years (range 18-29.8 years). The majority of the respondents were single (98.1%), living in their parental homes (90.8%), neither in school nor working (47.35%) and 14% were parents (range 1-3 children). The mean duration on ART was 12.4 years (± 4.0). Based on the BMI classifications by WHO, 38.5% of respondents were underweight (BMI < 18.5 kg/m2) and 7.3% were overweight (BMI ≥ 25.0 kg/m2). Unsuppressed viral load (>400 cell/mL) occurred in 13.4% of the sample. Most respondents had good HROQL (78.4%). The highest mean HRQOL score was recorded in the Physical domain (15.4 (± 2.9) and the lowest in the Environment domain 13.8 (± 2.7).

The results fitted using the multivariable logistic regression suggest the odds for good general QOL were increased amongst individuals with a higher level of education and

those who were employed. The odds for good general QOL were reduced for individuals with unsuppressed viral load (> 400 cells/mm2) and those who had illnesses (self-reported). The odds for good general QOL increased by almost two folds (OR = 1.97, 95% CI = (1.11 – 3.48)) when comparing respondents with higher level of education against those with lower education. The odds for good general QOL were increased for employed respondents OR = 1.73 (95% CI = (0.92 – 3.23) when compared to the unemployed group. Whereas the odds for good general QOL declined by almost two folds (OR = 0.60, 95% CI = (0.33 – 1.08)) amongst patients with VL > 400 cell/mm2 compared to those with VL < 400 cells/mm2. Also, respondents who were ill had lower odds ratios for good general QOL compared to those who were not ill (OR = 0.42, 95% CI = (0.25 – 0.70)).

The results of in-depth interviews with 45 respondents showed that the majority of YALPH were in good physical health and they had positive perspectives about the future including health, completing school, finding employment, marriage and childbearing. The main sources of social support for YALPH were close family members and health care workers (HCWs). However, worries and concerns about disclosure, fear of stigma, lack of financial independence, and limited social relationships and networks were the most identified stressors that put the YALPH at risk of compromised HRQOL. Some sub-groups of YALPH were at higher risk for poor HRQOL including: young mothers, YALPH who were aging out of institutional care, YALPH with disabilities and impairments, YALPH who were neither in school nor working and YALPH with maladaptive coping strategies.

Therefore, the promotion of the HRQOL of YALPH will require policies and interventions to increase educational attainment, provide employment and livelihood opportunities, promote good ART adherence and VL suppression, and effectively prevent and manage illnesses. Special attention should be paid to sub-groups of YALPH who are at increased risk of compromised HRQOL.

Key Words: HIV, AIDS, Quality of Life, Health-Related Quality of Life, WHOQOL-HIV BREF, perinatally HIV infected young adults, factors affecting HRQOL, determinants of HRQOL, policy.

Table of Contents

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS

ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARVs	Antiretroviral Drugs
BAIS	Botswana AIDS Impact Survey
BMI	Body Mass Index
BIDPA	Botswana Institute for Development Policy Analysis
CDC	Centers for Disease Control and Prevention
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HRQOL	Health Related Quality of Life
JSS	Junior Secondary School
OVC	Orphans and Vulnerable Children
IDI	In-depth interviews
MFDP	Ministry of Finance and Development Planning
MLGRD	Ministry of Local Government and Rural Development
MOBE	Ministry of Basic Education
MOHW	Ministry of Health and Wellness
PMTCT	Prevention of Mother to Child Transmission of HIV
MTCT	Mother to Child Transmission of HIV
MYSC	Ministry of Youth, Sports and Culture
NACA	National AIDS Coordinating Agency
NDP 11	National Development Plan 11
NSF111	National Strategic Framework 111
PMTCT	Prevention of Mother to Child Transmission
RNPE	Revised National Policy on Education
QOL	Quality of Life
RNYP	Revised National Youth Policy
SFP	School Feeding Program
SRH	Sexual and Reproductive Health
SSS	Senior Secondary School
ETSSP	Education and Training Sector Strategic Plan
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Program
VL	Viral Load
WHO	World Health Organization
YALPH	Young Adults Living with Perinatally Acquired HIV Infection

CHAPTER ONE

1.0 INTRODUCTION AND BACKGROUND

1.1 PERINATALLY HIV INFECTED YOUNG ADULTS IN BOTSWANA

Increased access to Highly Active Anti-Retroviral Therapy (HAART) in both high and low income countries has resulted in opportunistic infection avoidance, better physical health and reduced mortality among people living with HIV (Mutanga, Mutembo, Ezeamama, Song, Fubisha, Mutesu-Kapembwa, Sialondwe, Simuchembu, Chinyonga, Thuma & Whalen 2019:11; Fish, Judd, Jungmann & O'Leary 2014:244; and Gunther, Foisy, Houston, Guirguis & Hughes 2014:105). Resultantly, perinatally HIV infected adolescents are emerging into young adulthood in large numbers and having to adapt to living with a life-long, highly stigmatized infection that requires constant management for VL suppression while faced with the developmental tasks of this phase in life (Fish et al. 2014:243; and Osinde, Kakaire & Kaye 2012: 61). The stress of those two challenging situations can lead to negative coping in young adults living with HIV.

Perinatal HIV infection also referred to as vertical or mother-to-child transmission (MTCT) is the transmission of HIV infection from a woman to her child. Perinatal transmission of HIV can occur during pregnancy, labor and delivery, or breastfeeding. Due to the successful Prevention of Mother-to-child transmission (PMTCT) program and the widespread use of Antiretroviral Therapy (ART) in Botswana, there are few new cases of perinatal HIV infection. But there is a large cohort of children born before these advances who are emerging into young adulthood in large numbers. This study defines young adults as individuals aged approximately 18-30 years and focuses primarily on this age range. A young adult was considered to have perinatally acquired HIV infection if his/her mother was HIV infected according to clinical records or if s/he was found to be positive during infancy or early childhood without another documented explanation for exposure.

Young adults living with perinatally acquired HIV (YALPH) have to face the challenges related to growing up with HIV infection which may include mental health problems, side effects of HIV treatment, physical and developmental disabilities, psychological stressors, problems with long-term adherence to Anti-retroviral Therapy

(ART), self-disclosure of HIV diagnosis to sexual partners, parenting decisions, and settling down after transitioning from paediatric and adolescent HIV care settings to adult HIV care systems (Bucek, Mellins & Abrams 2019:465; Abrams, Mellins, Bucek, Dolezal, Raymond, Wiznia, Jurgrau, Bamji, Leu & Ng. 2018:157; and Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath & Ferrand 2014: 627).

YALPH must also confront the same challenges of young adulthood faced by other HIV negative youth. According to the Botswana Revised National Youth Policy (Ministry of Youth, Sports and Culture (MYSC) 2010: 3-4), the main challenges facing the youth in Botswana include poverty and unemployment; limited education and training opportunities; limited access to recreational, sport and art opportunities; food insecurity; insufficient life skills; low self-esteem; and poor access to business opportunities. Any or all of these factors may be risk factors for poor quality of life (QOL). Therefore, rather than focusing just on long-term disease management and prevention of onward transmission of HIV, policies and programs that support YALPH must also focus on promoting their wellbeing and QOL.

1.1.1 Epidemiology of HIV among Young Adults in Botswana:

Limited information exists regarding HIV prevalence among young adults in Botswana due to the lack of national-level surveillance data focusing specifically on this population. Young adults (18-30 years) are different from both adolescents (<18 years) and older adults (>30 years), however, they are often combined with one or the other in statistical reporting, research design, as well as in policy and program classification. As a result, not enough is known about the prevalence of HIV and or the special strengths and vulnerabilities of this population in Botswana. According to Botswana AIDS Impact Survey (BAIS) IV (Statistics Botswana 2014:9) HIV prevalence among people aged 20-24 and 25-29 years was 10.3% and 21.1% respectively as shown in Figure 1.

HIV infection in young adults consists of two different populations: those who acquired HIV infection through perinatal transmission and those who acquired HIV through sexual contact or other means. The course of HIV in these two populations may be different, however, the challenges faced can be similar, including the stigma and discrimination of HIV infection, the need for privacy, the need for disclosure of their HIV status to sexual partners and the need to prevent forward transmission of HIV (Tanner, Philbin, Chambers, Ma, Hussen, Ware, Lee & Fortenberry 2018:158).

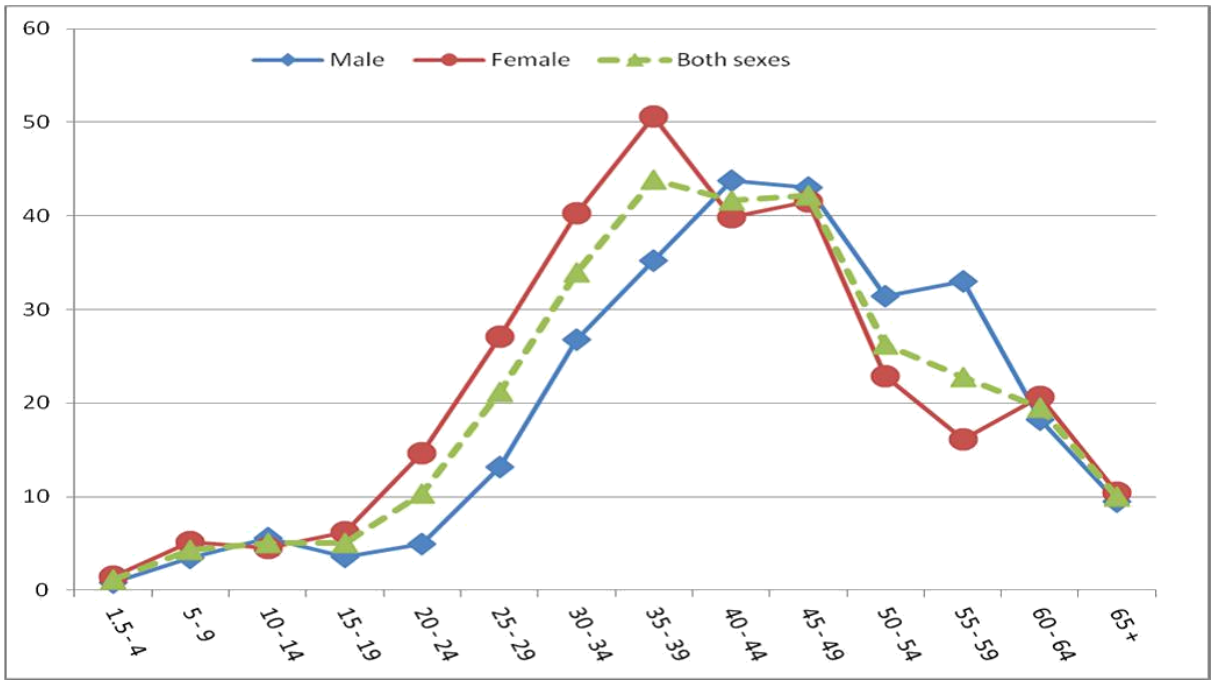

Figure 1: Botswana HIV Prevalence by Age Group and Sex
Source: BAIS IV (National AIDS Coordinating Agency 2014:9)

1.2 DEVELOPMENTAL TASKS OF YOUNG ADULTHOOD

This study defines young adults as individuals aged approximately 18-30 years and focuses primarily on this age range. According to human development theorists, young adulthood is a critical period of development, with long-lasting implications for a person's economic security, health, and well-being (Havighurst 1953:5; Erikson1994:46).

The concept of developmental tasks assumes that human development is characterized by a series of tasks that individuals have to learn throughout their lives. Some of these tasks are located in childhood and adolescence, whereas others arise during adulthood and old age (Havighurst 1972:45). According to Havighurst's biopsychosocial model of human development, a developmental task is one that arises predictably and consistently at or about a certain period in the life of the individual (Havighurst 1953:2). Havighurst further asserts that developmental tasks arise from three different sources including physical maturation, socio-structural and cultural forces, and personal values and aspirations (Havighurst 1972:45).

According to human development theorists, developmental tasks of young adulthood differ across cultures however the common critical ones include choosing a partner, establishing a family, childbearing and parenting, managing a home, and establishing a career (Erickson 1959:54 & Heckhausen, 1991:28). According to Erik Erikson's theory of psychosocial development, young adulthood (18-40 years) is a period marked by exploration and formation of personal relationships (Erickson 1959:54). According to Erickson, within their social networks, young adults formalize their identity, explore their social roles and most importantly, find support for stressors.

It is theorized that achievement of a certain developmental task will lead to happiness and to success with later tasks, while failure may result in unhappiness in the individual, disapproval by the society and difficulty with later tasks (Erickson 1994:38; and Havighurst 1953:5). It is also noted that the presence of a chronic illness such as HIV during this period can interfere with the achievement of these developmental tasks (De Santis, Lin, Mariotto, Siegel, Stein, Kramer, Alteri and Robbins 2014:252; and Sundh, Johansson, Larsson, Linden, Lofdah, Janson & Sandstrom 2015:175). In the context of Botswana, the start of young adulthood coincides with the legislative age of majority which is 18 years; the age at which individuals are legally considered adults (Botswana Children's Act of 2009:37). It is at this age that youth exit from the Government of Botswana's Orphans and Vulnerable Children (OVC) Support Program, transition to the Destitute Persons Program, live independently or find other sources of support.

Given the critical nature of young adulthood within the life course and the potential negative effects of HIV infection as a chronic illness, it is important to study the HRQOL of YALPH and to identify their perspectives regarding how they could be supported to successfully achieve the developmental tasks of this important stage in life. Therefore, this study aimed to highlight the plight of YALPH and to recommend policies and interventions to promote their HRQOL.

1.3 THE CONCEPT OF HEALTH-RELATED QUALITY OF LIFE (HRQOL).

1.3.1 Definition of HRQOL:

The term HRQOL is a combination of two terms, namely health and quality of life (QOL). The constitution of the World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely absence of disease and infirmity” (WHO 1946:100). As a broad WHO concept, QOL is described as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHOQOL Group 1998:551).

The WHO also describes QOL as a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (WHOQOL Group1998:551). When QOL is considered in the context of health, disease and treatment, it is commonly referred to as HRQOL to differentiate it from other aspects of QOL. According to the WHO, HRQOL is “the functional effect of a medical condition and/or its consequent therapy upon a patient” (WHOQOL Group 1998: 552).

Since health is a multidimensional concept, HRQOL is also multidimensional and includes domains related to physical, mental, emotional, and social functioning. HRQOL goes beyond the direct measures of health and focuses on the QOL consequences of health status. Therefore, those definitions narrow down the focus of HRQOL to the effects of health, illness and treatment on QOL. Therefore, although the term QOL is sometimes used interchangeably with HRQOL, QOL is a broader construct that encompasses aspects of life that may not be related to healthcare services. HRQOL comprises the components of QOL that are directly related to health status and HRQOL instruments are intended to measure how disease and treatment are experienced by individuals. Therefore, throughout this study, the term HRQOL will be used.

1.3.2 The importance of Assessing HRQOL:

HRQOL is one of the most used subjective aspects in measuring the impact of chronic disease conditions such as HIV and is also used as a key outcome variable for validating current treatment approaches, assessing their effectiveness as well as in the approval of new therapeutic regimens (O'Connell & Skevington 2012:452; Smit, Brinkman, Geerlings, Smit, Thyagarajan, Sighem, de Wolf & Hallett 2015:810; and Etenyi, Okalebo, Oluka, Sinei, Osanjo, Kurdi, Meyer, Godman & Opanga 2018:984).

According to WHO, data from HRQOL assessments can be used to inform and mobilize support for health policies and legislation, guide needs-based allocation of resources and monitor the effectiveness of interventions and programs at all levels hence incorporating the service recipient's voice into health care decision making (WHOQOL Group 1998:4). According to the Centers for Disease Control and Prevention (CDC), HRQOL assessment data can guide the identification of subgroups with poor perceived health and help to inform programs to improve their situations and avert more serious consequences in a clinical setting (CDC HRQOL Concepts 2018:1). Information on HRQOL can be used to identify which groups are at risk of poor or declining QOL and can help inform interventions to target groups most at risk of poor QOL.

Additionally, and most importantly measuring HRQOL can help patients feel that their service provider acknowledges that their life quality is also an important part of their clinical care and an outcome that may improve provider-patient relationships. This sense of shared appreciation for the importance of HRQOL may in and of itself improve patient satisfaction and outcomes (CDC HRQOL Concepts 2018:1).

1.3.3 Effects of ART on HRQOL:

ART is a course of medication provided to people infected with HIV aimed at increasing CD4 cell counts, an indicator of immune system status, and decreasing HIV VL, which indicates the amount of circulating virus in the blood. Since their introduction, ART medications have become increasingly more effective, with fewer side effects. As a result of increased availability and efficacy of ART, it is now expected that someone diagnosed with HIV today who receives proper care and treatment may be able to achieve a normal or near-normal life expectancy (Astuti & Maggiolo 2014:1; and Lungren, Babiker & the INSIGHT START Study Group 2015:

808). Studies have also proven the efficacy of ART for the prevention of HIV transmission (HIV Prevention Trials Network (HPTN) 052 study 2011:494; Cohen, Chen, McCauley et al. 2011:493).

However, despite these advances in treatment, several significant QOL challenges for PLWH on ART persist. Antiretroviral drugs pose a challenge for HRQOL as they are associated with significant side effects in addition to the potential for drug toxicities and interactions (Gaida, Truter, Grobler, Kotze & Goldman 2016:377; and Kalemeera, Mbago, Mubita, Naikaku, Gaida & Goldman 2016:782). For YALPH starting on ART early in life means they are faced with challenges of remaining adherent for longer periods and having to deal with the psychological effects of having to take medicines every day for the rest of their lives that remind them of their HIV infection. Any or all of these factors may lead to poor HRQOL.

Poor HRQOL may lead to problems with medication adherence (Ndubuka, Lim, Van der Wal, Ehlers 2016:1; and Barosso, Leserman, Harmon, Hammill & Pence 2015: 78), which in turn can lead to HIV illness-related issues and treatment resistance (Degroote, Vogelaers & Vandijck 2014:6). For those reasons, monitoring the patient's experience beyond their ART-related outcomes, such as measuring HRQOL as its own endpoint in clinical settings is critical.

1.3.4 HRQOL Measurement Tools:

Various instruments have been used to measure HRQOL. HRQOL assessment instruments can be classified as either generic or disease-specific (Wacker, Jörres, Karch, Wilke, Heinrich, Karrasch, Koch, Schulz, Watz, Leidl, Vogelmeier, Holle & the COSYCONET-Consortium 2016:2). Generic instruments measure all dimensions of HRQOL and can therefore be applied in healthy populations as well as in any clinical population regardless of the type of health condition (Cooper, Clatworthy, Harding, Whetham & Emerge Consortium 2017:19).

Disease-specific HRQOL tools measure health status in specific patient groups, single disease states or areas of function. In contrast to generic instruments, disease-specific instruments focus on those dimensions that are likely to be affected by a specific condition and/or its treatment. Such questionnaires describe disease-specific HRQOL domains in more detail and are generally considered to be more sensitive to

change in clinical applications for which they were developed compared with generic questionnaires (Wacker et al.2016:2; and Cooper et al. 2017:19).

HRQL in this study was measured using the WHOQOL-HIV BREF, an HIV disease-specific instrument developed and validated by the WHOQOL Group for measuring QOL among PLWH (O'Connell & Skevington 2012:252). The WHOQOL- HIV BREF is a shorter version of the WHOQOL-BREF which is an abbreviated version of the WHOQOL-100 (O'Connell & Skevington 2012:252). The WHOQOL- HIV tools were developed by WHO as a cross-cultural instrument and validated through an international field trial in 15 countries worldwide including two countries in Southern Africa - these being Zambia and Zimbabwe.

The WHOQOL-HIV BREF is a multi-dimensional instrument comprising 31-items covering six domains namely: Physical (4 items), Psychological (5 items), Level of independence (4 items), Social relationships (4 items), Environment (8 items) and Spirituality/religion/personal beliefs (4 items). Two items aim to assess the overall HRQOL and General Health Perception.

Each domain has a set of facets and denotes a description of a behaviour, a state of being, a capacity or potential, or a subjective perception or experience (O'Connell and Skevington 2012:457). Individual items on the WHOQOL-HIV BREF are rated on a five-point Likert scale, ranging from one (low or negative perception) to five (high or positive perception). Table 1.1 shows the WHOQOL-HIV BREF domains and facets. The WHOQOL-HIV BREF provides a profile of QOL with scores ranging from 4 (poorest QOL) to 20 (best QOL) across the six domains.

The WHOQOL-HIV BREF was identified as the most suitable HRQOL instrument for this study due to its HIV specificity, provides a snapshot of HRQOL, can distinguish between different stages of HIV disease progression, has good psychometric properties, and has discriminant validity (Meemon, Peak, Yenchai & Wan 2016:698; and Cooper et al. 2017:19). The WHOQOL-HIV BREF had been validated in different cultural settings across multiple countries (Bakiono, Guiguimdé, Sanou, Ouédraogo & Bakiono 2015:4; Zhu, Liu & Qu 2017: 475; Karkashadze, Gates, Chkhartishvili, DeHovitz & Tsertsvadze 2017:672; Ndubuka, Lim, van der Wal & Ehlers 2016:475; Vigiri, Meyer, Godman & Gous 2018:121; and Tesfay, Gebremariam, Gerbaba & Abrh 2015:1).

A systematic review of reviews of international assessments of HRQOL in PLWH identified the WHOQOL-HIV BREF instrument to be one of the most cross-culturally valid measures and therefore a good choice for international assessment of HRQOL in PLWH (Cooper et al. 2017:19). In addition, the completion and administration process of the questionnaire is simple, providing a quick measure of HRQOL; consequently, making it ideal for administration to PLWH in busy clinics (O'Connell and Skevington 2012:459). The tool can be administered to those who are non-literate or self-administered and takes approximately 15-20 minutes to complete.

TABLE 1.1 WHOQOL-HIV BREF DOMAINS AND FACETS

DOMAINS	FACETS
Domain 1 – Physical	Pain and discomfort Energy and fatigue Sleep and rest Symptoms of PLWHIV
Domain 2 – Psychological	Positive feelings Cognitions Self-esteem Body image and appearance Negative feelings
Domain 3 – Level of Independence	Mobility Activities of daily living Dependence on medication or treatment Work capacity
Domain 4 – Social Relationships	Personal relationships Social support Sexual activity Social inclusion
Domain 5 – Environment	Physical safety and security Home environment Financial resources Health and social care New information or skills Recreation and leisure Physical environments Transports
Domain 6 – Spirituality	Spirituality/Religion/Personal beliefs Forgiveness Fear of the future Death and dying
Overall Quality of Life	General QOL & General health perception (general item on QOL and health)

1.4 KEY YOUTH FOCUSED POLICIES AND PROGRAMS IN BOTSWANA

The Government of Botswana and its partners have established diverse health, social welfare, and youth empowerment policies and programs that aim to promote the health and wellbeing of all youths in Botswana. These include:

1.4.1 Health Care Services:

All people in Botswana have access to free health care services through the public health care system. The Government of Botswana provides a primary health care system that offers essential health services in an evenly accessible way to all Batswana. Health services in Botswana are provided within the framework of the Revised National Health Policy (Ministry of Health 2011:1-41) and the Essential Health Service Package (EHSP) for Botswana (Ministry of Health 2010:1-142). Additionally, within the framework of the National Health Policy and the EHSP, youth in Botswana have access to comprehensive sexual reproductive health (SRH) services such as antenatal, delivery and post-natal care, treatment of sexually transmitted infections (STI), family planning and cervical cancer screening services.

1.4.1.1 The Botswana National HIV Treatment and Care Program

YALPH have access to clinical and psychosocial support services as part of the National HIV/AIDS program. The Botswana National HIV/AIDS response is guided by the Revised National Policy on HIV/AIDS (National AIDS Coordinating Agency 2012:1-19) whose objectives include preventing the spread of HIV infection and reducing the socio-economic impact of the disease; creation of a policy environment for the provision of adequate and equitable care and support to those infected and affected with HIV and AIDS; and reducing stigma and discrimination towards PLWH in society.

The program is also anchored on the priorities and strategies outlined in the National HIV/AIDS Strategic Framework III (National AIDS Coordinating Agency 2018:7). The main goals of the NSF III include preventing new HIV infections; and scaling up treatment, care and support services for HIV infected people (NACA 2018:8). The NSF III is anchored in the Eleventh National Development (2017-2023) whose goals include improving access to quality health care services, prevention of new HIV

infections and working towards ending AIDS as a public health threat by 2030 (Ministry of Finance and Development Planning 2017:190).

At the global level, the NSF III is linked to the United Nations Sustainable Development Goals particularly: (i) Goal 3 on reducing maternal and child mortality, preventing early and unwanted pregnancies, ending the epidemics of HIV and TB, improving access to health services and promoting mental health and wellbeing; (ii) Goal 5 on the elimination of violence including sexual violence against girls and women in all settings, elimination of harmful practices such as early and forced marriages, increasing access to sexual and reproductive health and reproductive rights; (iii) Goal 10 on promoting inclusion, reducing inequality and addressing stigma and discrimination; (iv) Goal 17 on ensuring sustainable financing for sustainable development through increased domestic funding, and strengthening integrated service delivery and strengthening monitoring and reporting.

Part of the national HIV/AIDS Program is the Botswana National ART Program which was launched in 2002. The Program provides free ART to all qualifying Batswana under the “Treat all” policy. In addition, developmental tasks of young adulthood include childbearing and parenting. Therefore, interventions to prevent the transmission of HIV to their offspring are key to the wellbeing of YALPH. As part of the National ART Program, YALPH can access Prevention of Mother to Child Transmission (PMTCT) services. According to the Botswana Global AIDS Response Progress Report for 2014, PMTCT was available in all the 634 health facilities that provide maternal and child health services (NACA 2014:20). Results of the Botswana AIDS Impact Survey IV of 2013 showed that the (PMTCT) program in Botswana had reduced transmission of HIV from mother to child to as low as 2.2% (NACA 2014:10).

1.4.2 Educational Policies and Programs:

The Government of Botswana through the Ministry of Basic Education and the Ministry of Tertiary Education, Research, Science and Technology has a series of policies and programs that benefit youths within the school environment. The Revised National Policy on Education (RNPE) of 1994 (Republic of Botswana 1994) is the main policy framework for the provision of education in Botswana. The RNPE promotes an inclusive education system and provision of special education to

vulnerable youths including those with special education needs, disabilities and chronic illnesses such as HIV (Republic of Botswana 1994:7). The first ten years of education ('basic education') are available to all children. Parents are charged a 'co-payment' for education, but the children of those in lower-income groups receive free education.

1.4.2.1 Special Education for Learners with Disabilities:

Disabilities and impairments are common among HIV infected youth and they have profound negative effects on school performance and achievement (Anabwani, Karugaba, Gabaitiri 2016:6). According to the Botswana National Policy on Care for People with Disabilities (2011:5), disability is "a long-term impairment, be it physical, mental, intellectual, or sensory whether inherited or acquired which, when combined with environmental and societal barriers limits the person's ability to function on an equal basis with others who have no impairment".

According to the Botswana Demographic Survey of 2017 (Statistics Botswana 2017: 60), out of 2,154,863 of the population surveyed a total of 90,945 individuals reported disabilities, accounting for a prevalence rate of 4.2 percent. Among the disabled population, sight/visual impairment accounted for the highest proportion of disabilities at 49.4 % and hearing impairment constituted 28.7%. Of these, 4583 sight/visual and 2062 hearing-impaired people were still in school.

Mechanisms that are in place to improve access for youth with special education needs include special education units in schools, provision of equipment and infrastructure in mainstream schools to support learners with disabilities, as well as integrating learners with special education needs and disabilities into the mainstream school system. According to the Secondary Education Statistics Brief for 2015 (Statistics Botswana 2015:9), there was one government Junior Secondary School (JSS) and one Senior Secondary School (SSS) with visual impairment special education units, two JSS and one SSS with hearing impairment special education units.

1.4.2.2 The Botswana School Feeding Program:

There is evidence that food insecurity and malnutrition are problems in many households in Botswana due to various factors including inadequate food consumption, lack of food, lack of knowledge on food processing and preparation, poor dietary habits and poverty (SADC 2019:8; Letamo & Navaneetham 2014:5-6; Mendoza, Matshaba, Makhanda, Liu, Boitshwarelo & Anabwani 2014:66; and Anabwani et al. 2016:7). Additionally, according to the Botswana Demographic Survey of 2017, out of 2,154,863 of the population that was surveyed, 61.4 percent of males and 35.4 percent of females were underweight. On the same note, 14.4 percent of females and 4.7 percent of males were overweight (Statistics Botswana 2018:57-58).

The Botswana School Feeding Program (SFP) is universal for all students from primary to secondary schools making it the largest social protection intervention employed by the Government of Botswana in terms of coverage (Drake, Woolnough, Burbano, Carmen & Bundy 2016:49). The SFP acts as a safety net providing direct nutritional support to learners living in vulnerable and food insecure contexts. School meals offer a source of readily available essential nutrients likely to be missing in the student's home diets (Drake et al. 2014:2). One daily mid-morning meal provides a third of the daily energy requirements and in the Remote Area Dwellers' Districts, a second meal (the same as the mid-morning meal) is provided (Drake et al. 2016:59).

The Ministry of Local Government and Rural Development (MLGRD) is the institution responsible for program implementation, but school feeding is also one of several vulnerable group feeding and food security programs co-ordinated as part of the Revised National Food Strategy under the Ministry of Finance and Development Planning (Republic of Botswana, 2000:5).

1.4.2.3 School Guidance and Counselling (G&C) Program:

The MOESD provides Guidance and Counselling (G&C) services in schools to cater for the personal, social, health, academic and vocational needs of learners. The G&C program is founded on the developmental and preventative counselling approaches. The developmental approach to counselling adopts a life-span approach where an individual's self-development is aided in a non-crisis atmosphere and prepares students for life challenges even before they arise. The preventive aspect focuses on

specific concerns to empower students with the skills on how to handle or cope with such issues (Piajet 1952:56-59). However, students who are HIV infected may not utilize G&C services due to the fear of HIV-related stigma which has been found to be highly prevalent in schools in Botswana (Anabwani et al. 2016:6).

1.4.2.4. Tertiary and Technical Education Support:

Educational attainment is a major determinant of QOL. Tertiary and technical education support is a program by the education sector to sponsor eligible OVC to tertiary and technical education. For example, beginning in 2015, the Ministry of Education and Skills Development established a special program to sponsor eligible vulnerable youth for tertiary and technical education. An example of a specific initiative under this arrangement is the “Target 20,000 Up-skilling and Up-scaling Project” established by the Ministry in 2015 targeting unemployed youth aged below 35 years for sponsorships and placement into tertiary institutions. The project had a special dispensation for unemployed youth and those with special educational needs.

Technical and Vocational Education and Training (TVET) in Botswana is delivered at different levels from certificate to diploma in different types of institutions. The institutions include government-owned Technical Colleges (7) and Brigades (35). Accredited private training institutions also offer vocational training. The Department of Technical and Vocational Education and Training under the Ministry of Education and Skills Development has the overall responsibility for planning and implementing technical and vocational education in Botswana. Historically the brigades were established by communities to absorb children who would have failed to progress through secondary schools and were managed through a consultative process with the Government. In 1996 the brigades were taken over by the Government for improved coordination. In 2014, the Government of Botswana approved partnerships with the private sector training institutions in the leasing and sharing of brigade facilities.

Brigade centers are autonomous, community-based, institutions that provide practical on-the-job training for Botswana youth. The types of training offered in those institutions include auto mechanics, agriculture, construction, office studies, carpentry, electrical, drafting, general maintenance, machinery, plumbing, tannery, textiles and welding.

1.4.3 Social Welfare Services for Vulnerable Youth

1.4.3.1 The OVC and Destitute Persons Support Program

The HIV epidemic caused an unprecedented increase in the number of orphans and vulnerable children in Botswana. This led to the establishment of the Orphans and Vulnerable Children (OVC) care program by the Ministry of Local Government and Rural Development (MLGRD). The overall goal of the OVC support program is to improve the QOL of OVC by ensuring that they receive optimal care and support.

The services which are provided under the OVC support program include food support, clothing, school fees, school uniform, transport fares and other school-related costs, accommodation based on the needs of the child, pocket money, toiletry and medical fees. Other services include psychosocial support (PSS) which aims to meet the social, mental, emotional and physical needs of OVCs and their families. Furthermore, OVC are assisted to access tertiary education through the OVC Special Dispensation on post-secondary education support. In 2015, a total of 35, 076 registered orphans were assisted with various services (MLGRD 2016:10).

Youths exit the OVC support program after attaining the age of 18 years. However, there are policy provisions that OVC who are 18 years and over and who remain vulnerable or destitute are transferred to the Destitute Program or are helped to access other youth empowerment schemes. The Revised National Policy on Destitute Persons of 2002, defines a destitute as “an individual who, due to disabilities or chronic health condition, is unable to engage in sustainable economic activities and has insufficient assets and income sources” (MLGRD 2002:25). Following this policy, persons who exit the OVC Care Program after attaining the age of 18 years should be immediately assessed by the social workers to ensure a continuum of care through the destitute program.

However, an assessment of the Botswana OVC care program conducted by USAID in 2010 revealed that there are limited graduation programs or services to prepare older OVC before turning 18 years, the age at which they are no longer eligible for mandated benefits. The assessors recommended setting up well-funded and coordinated graduation efforts for OVC as they approach the age of 18 years including vocational training, life skills education, job internships with private companies, and psychosocial support. This could include prioritizing caregivers of

OVC and older OVC for income-generating or vocational programs (Feranil, Herstad, Jallow & Mbuya-Brown 2010:38-39).

A follow-up assessment of the Botswana OVC care program conducted by the MLGRD and UNICEF in 2016 revealed similar gaps in deliverance at the local government level mainly due to insufficient resources, understaffing and lack of sufficiently trained staff particularly in psychosocial support. In addition, there were no consequences of not following policy and program guidelines by key actors such as social workers and magistrates (MLGRD 2016:30, 33, 36).

The evaluations also highlighted limited graduation programs or services to prepare older OVC before turning 18 years the age at which they are no longer eligible for mandated benefits. Most of the beneficiaries either are lost to follow-up or transfer into the destitute program. The assessors recommended setting up well-funded and coordinated graduation efforts for OVC as they age out of the OVC care program including vocational training, life skills education, job internships with private companies and psychosocial support and capacitating of caregivers with income-generating activities. They also recommended the capacity building of service providers including (politicians, police officers, magistrates, social workers and other key actors) in handling and support of OVC (MLGRD 2016:36).

1.4.3.2 Institutional Care:

Due to the epidemiology of the early HIV epidemic in Botswana, many mothers died from AIDS-related illnesses with some of their children raised by members of their extended family or placed in institutional care. Hence there are YALPH in institutional care and some of them have lived there since childhood. In Botswana, children enter institutional care after determination and approval from a government social worker, that placement in institutional care will protect them from extreme poverty, abuse, neglect, and/or help them access essential services in line with the legislation on Children in Need of Protection as outlined by the Botswana Children's Act of 2009 (Republic of Botswana 2009:57).

In 2019, there were 5 institutional care facilities in Botswana. These include the three SOS children's villages, Child-line Botswana and Mpule Kwelagobe facility. The standard requirement is that youth exit institutional care between the ages of 18–24 years when they reach the age of majority or when they graduate from school.

However, there is limited data on transitioning and reintegration of youths who are aging out of institutional care back into their families of origin or independent living in the community in Botswana.

However, studies conducted in the USA and other countries showed evidence of the difficulties of transitioning to adulthood for former institutionalized young adults including poor school achievement, unemployment and difficulties achieving financial independence (Courtney & Dworsky 2006:10; and Courtney 2010:177-133), more mental health problems and high rates of drug and alcohol abuse and dependence than the general population (Keller, Salazar & Courtney 2010:32) and poorer physical health than other young adults (Ahrens, Courtney, McCarty, Simoni & Katon 2010: 126).

The United Nations Guidelines for the Alternative Care of Children provides countries with guidance on preparing the transitioning of young people from the alternative care system to independent living (UNICEF 2010: 26-28). The guidelines emphasize the need for individual planning to involve the youth in determining the most suitable option for them and how it is to be organized, ongoing educational and vocational training opportunities to help them become financially independent and generate their income and the need for special support for those with disabilities and other special needs who are leaving the care (UNICEF 2010:26-28). The organizations discharging YALPH from long-term institutional care need to take cognizance of these guidelines.

1.5 YOUTH DEVELOPMENT POLICIES AND PROGRAMS

Youth development in Botswana is undertaken through the Ministry of Youth Sports and Culture (MYSC) and within the framework of the Revised National Youth Policy (RNYP) of 2010 (MYSC 2010).

The RNYP defines youth as the age bracket of 12-29 years. The main youth-related problems highlighted by the RNYP include alcohol and substance abuse among youth; high unemployment rate; HIV/AIDS and associated diseases; poverty; hunger; limited recreational, sport, and art opportunities (MYSAC 2010:6-8). The priority target groups for the RNYP have been listed to include: youth with disabilities; out of school and unemployed youth; adolescent parents; youth living with HIV and AIDS or other life-threatening diseases; and orphans and adolescent caregivers.

The policy has a special dispensation for the economic empowerment of vulnerable youth. The specific strategies under this dispensation include: i) Enhance participation of vulnerable youth groups to assess their needs and livelihoods in policy development; ii) Design and implement effective special support programs; iii) provide appropriate infrastructure, facilities and services; IV) Develop programs to reduce stigmatization; V) Develop programs and projects for young people living with HIV and AIDS and network with the regional and international program of young ambassadors positively living with HIV and AIDS; VI) Upgrade and expand specialized institutions serving vulnerable youth; and, VII) Involve vulnerable youth groups in Adolescent Sexual Reproductive Health Programs.

The MYSC to expand and improve opportunities for youths has established a series of programs that are open to all Botswana citizens. The key policies and programs include the following:

1.5.1. Youth Business Financing Schemes:

These are programs funded by the Government of Botswana and coordinated by the MYSC to address the issue of unemployment through the development of sustainable business projects. Some of these programs are funded through grants and loans and others through contributions from both the beneficiaries and the funder. Some of the micro-financing schemes include Citizen Empowerment Development Agency (CEDA); Young Farmers Fund; Youth Development Fund (YDF); Remote Area Development Program (RADP); Integrated Support Program for Arable Agricultural Development (ISPAAD); and Livestock Management and Infrastructure Development (LIMID).

1.5.2. The Botswana National Service Program (BNSP) or Tirelo Sechaba

The program was introduced to promote the spirit of voluntarism among the youth, inculcate a sense of patriotism and duty to serve one's community, and also to allow the youth to acquire work experience and to gain lifelong skills. The program coordinated by the MYSC targets youths aged 20-30 years, currently unemployed and out of school with no formal tertiary education. The youth are placed in different Government Departments, Non-Government Organizations, public and parastatal sector institutions and different community programs to acquire work skills and experience and increase their chances of gaining employment in the future.

1.5.3. National Internship Program:

The National Internship Program is a program of the MYSC to offer unemployed citizen-graduates of Botswana a chance to develop work skills and experience that will support them in the transition from school-life/academia to the working world through attachments in various organizations in Botswana and abroad. The program targets youth under the age of 35 years, who have graduated from a College or University program either locally or internationally. The program places graduate students from various academic fields to government and private sector offices to enable them to acquire practical work experience.

1.5.4 Botswana Public Works Program:

The program is an initiative of the Ministry of Local Government and Rural Development aimed at short term employment support and relief. The program is designed to maximize the employment of unskilled and semi-skilled labour in the implementation of labour-based initiatives and maintenance of government facilities. Projects include street sweeping, bush clearing and grass cutting in public places, de-bushing of roads and managing fire breaks, etc.

This study will explore how YALPH can access and utilize those health, social welfare and youth development policies and programs to promote their HRQOL.

1.6 STATEMENT OF THE RESEARCH PROBLEM

Due to the successful rollout of the Antiretroviral Therapy Program in Botswana, perinatally HIV infected adolescents are emerging into young adulthood in large numbers. Young adulthood (spanning the ages of approximately 18-30 years) is a critical period of human development, with long-lasting implications for a person's economic security, health and well-being. From a developmental standpoint, young adults are different, biologically and psychologically, from both adolescents and older adults in ways that affect their decision making, health, and behavior. From a social point of view, many YALPH confront major challenges in making a successful transition to adult roles in the presence of HIV which is a stigmatised illness. The YALPH have to face the challenges related to growing up with HIV infection and also confront the same challenges faced by other HIV negative youth including

unemployment and poverty among others. In the context of Botswana, the start of young adulthood coincides with the legislative age of majority which is 18 years (Botswana Children's Act of 2009: 37). This is the age at which youth exit from the Government of Botswana's OVC Support Program, and are expected to live independently or find other sources of support. It is also a time for transitioning from paediatric to adult health care system, from parental care to self-sufficiency and for some YALPH, transition from institutional care back to their homes of origin or into independent life in the community. Any or all of these factors may be risk factors for poor HRQOL. Therefore, it was important to conduct this study to identify the factors that put YALPH at risk of poor HRQOL and to develop policy recommendations to support them.

1.7 SIGNIFICANCE OF THE STUDY

Although there was a growing number of YALPH in Botswana, relatively little was known about their HRQOL. To the investigator's knowledge, before this study was conducted HRQOL had not previously been examined in Botswana among YALPH. As a result, little was known about the needs, experiences and factors affecting the wellbeing and HRQOL of YALPH in Botswana. Although two studies had been conducted on QOL in PLWH in Botswana (Phaladze 2005:120; and Ndubuka et al. (2016:3), there was no research on the HRQOL of YALPH. To bridge the information gap, this study was conducted to assess the HRQOL, identify the determinants of HRQOL of YALPH and get their perspectives on how their HRQOL could be promoted. The information gathered on the HRQOL would be of benefit to the MOHW and other funders in determining the resource allocation that is necessary for interventions to optimize the HRQOL of YALPH. Furthermore, assessing the HRQOL of YALPH was important to appreciate their perspectives regarding the quality of care they receive from their families, HCWs and other providers and how to enhance it to promote their HRQOL.

1.8 PURPOSE OF THE STUDY

The primary purpose of this study was to propose policy guidelines to promote the HRQOL of YALPH in Botswana. The study aimed to draw attention to young adulthood as a distinct and important period in the life course of young people who are growing up with perinatally acquired HIV. According to the WHO, the information generated from HRQOL assessments can be used to inform and mobilize support for health policies and legislation, guide needs-based allocation of resources, and monitor the effectiveness of interventions and programs at all levels hence incorporating the service recipient's voice into health care decision making (WHOQOL Group 1998:4). This study provides an in-depth understanding of the lived experiences, strengths, challenges, and vulnerabilities of YALPH and guidance on policies that are needed to enhance their HRQOL. The findings of this study will also demonstrate the usefulness of assessing HRQOL as part of treatment, care and support for YALPH. The results will inform priorities for research and provide baseline information against which the impact of future programs could be assessed.

1.9 RESEARCH OBJECTIVES

1. To describe the socio-demographic and clinical characteristics of YALPH who enrolled on ART at Botswana-Baylor.
2. To measure the HRQOL of YALPH enrolled on ART at Botswana-Baylor using the WHOQOL - HIV BREF instrument.
3. To identify the social demographic and clinical factors which were associated with HRQOL among YALPH enrolled on ART at Botswana-Baylor.
4. To qualitatively explore the perspectives of YALPH on how their HRQOL could be promoted.
5. To use the findings of the study to propose policy guidelines to promote the HRQOL of YALPH in Botswana.

1.10 RESEARCH QUESTIONS

To meet the purposes of the study, five research questions were explored:

1. What proportion of the sampled YALPH is experiencing poor or good HRQOL?
2. Is there a correlation between the social-demographic characteristics of YALPH (age, gender, education, employment) and their HRQOL?
3. Is there a correlation between clinical characteristics of YALPH (duration on ART, CD4 cell count, VL level, BMI, illness) and their HRQOL?
4. What are the perspectives of YALPH regarding how their HRQOL could be promoted?
5. What policies are needed to promote the HRQOL of YALPH in Botswana?

1.11 ASSUMPTION

At the start of the study, it was assumed that social-demographic factors (gender, age, level of education, and employment status) and clinical factors (duration on ART, VL levels, CD4 cell count, BMI and self-reported illness) determine the HRQOL of YALPH.

1.12 THEORETICAL FOUNDATIONS OF THE STUDY

The conceptual model underpinning this study was the Ferrans Conceptual Model of HRQOL. This conceptual model was first developed by Wilson and Cleary (1995:59-65) and further revised by Ferrans, Zerwic, Wilbur & Larson (2005:366-342). The model was developed to help explain the relationships of clinical variables that relate to HRQOL (Figure 2).

A systematic review of HRQOL conceptual models by Bakas, MacLennon, Carpenter, Buelow, Otte, Hanna, Ellett, Hadler & Welch (2012:12) recommended the use of the Ferrans Conceptual Model of HRQOL because it is extensively referenced in HRQOL literature, it provides clear conceptual and operational definitions and appears to have the greatest potential to guide HRQOL research and practice. Additionally, since the model incorporates individual characteristics with environmental characteristics, it would be a useful model for guiding HRQOL research in YALPH since their wellbeing

maybe directly affected by both internal factors (such as biological/physiological variables, personality, values and preferences) as well as characteristics of the environment (such as social support, quality of relationships and stigma).

As shown in Figure 2, the Ferrans Conceptual Model of HRQOL is presented as a taxonomy of patient outcomes that link the characteristics of the individual to the characteristics of the environment. The model highlights the influence of health related factors (in the central boxes), in addition to characteristics of the individual and the environment on QOL. The model proposes causal linkages between the different types of patient outcome measurements which are described by Ferrans et al. (2005: 336-342) as follows:

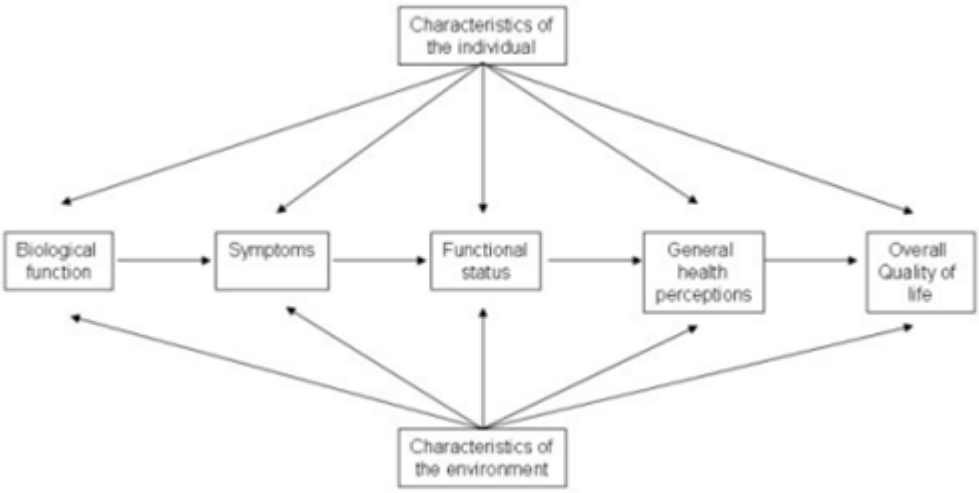

Figure 2. Ferrans Conceptual Model of HRQOL
Source: Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual Model of Health-Related Quality of Life. Journal of Nursing Scholarship, 37, 336–342.

Biological Function: The first variable the biological and physiological function refers to is the physical state of the individual. It encompasses molecular, cellular, and whole organ level processes. In the HIV/AIDS field, biological function includes such measurements as laboratory tests (CD4 cell count, VL, body mass index (BMI) and other clinical indicators that help to monitor the progression of HIV infection. In this study, biological function was measured by CD4 cell count, VL and body mass index (BMI) which were abstracted from respondents' medical records maintained at Botswana-Baylor.

Symptoms: The symptom status may be described theoretically as any psycho-physical, emotional or cognitive state that the individual may subjectively experience at the time of assessment. Symptom status consists of physical, emotional and psychological symptoms that the patient may subjectively experience. It also considers a person's perception of an abnormal physical, emotional, cognitive state or a perception, feeling or even belief about the state of the body. It includes mental health and emotional/psychological aspects such as fear, worry and frustration. Depressive symptoms and mental health are included in this definition.

In view of the WHOQOL-HIV BREF instrument, domain 1 and all its facets (pain and discomfort, energy and fatigue, sleep and rest, and symptoms of PLWH) are considered under this measurement.

Functional status: Functional status refers to one's ability to perform specific tasks or functions such as the ability to perform activities of daily living (ADL). Functional status is an individual's ability to perform tasks in multiple domains such as physical function, social function, role function and psychological function. Functional status may include vision and hearing, mobility and mental status (cognition and affect). Functional status is usually subjectively self-reported by the patient but can also be assessed by others. Assessment of functional status may help to indicate presence and severity of disease and to measure a person's need for care.

In view of the WHOQOL-HIV BREF instrument, domain 3 (Level of Independence) and all its facets (mobility, activity of daily living, dependence on medications or treatments, and work capacity); and domain 4 (Psychological) and its facets (positive feelings, thinking/learning/memory/concentration, self-esteem, body image and appearance, and negative feelings) fall under this measurement.

General health perceptions: General health perceptions are the way individuals perceive their health, based on the integration of biological factors, symptom status, and functional status combined with the effect of the disease on the individual. General health perceptions take into account the weights and values that the patient attaches to symptoms or functional abilities. Two defining characteristics of general health perceptions include: (a) they integrate all the components that come earlier in the model, and (b) they are subjective in nature, a synthesis of all the various aspects of health in an overall evaluation.

A single overall health item from the WHOQOL – HIV BREF instrument asks how the participant would rate his or her health during the last 2 weeks. This is a five-point Likert scale question, with responses that range from very poor to very good, and include a neutral midpoint (neither poor nor good). A higher score indicates better perceived health.

Overall quality of life: Overall QOL describes how happy or satisfied an individual is with all aspects of his or her life. Overall QOL is one's subjective appreciation or satisfaction with his or her life as a whole. A single overall QOL item from the WHOQOL HIV BREF instrument asks how the participant would rate his or her QOL during the last 2 weeks. The question is assessed on a five-point Likert scale, with responses that range from very poor to very good, and include a neutral midpoint (neither poor nor good). A higher score indicates better perceived overall QOL.

Characteristics of the individual: Characteristics of the individual pertain to factors or correlates that contribute to defining a person's life situation and these include demographic descriptors. For this study, measures assessing the characteristics of the individual were collected from the respondents and their medical records including (age, gender, level of education, employment status, place of residence and marital status). Domain 6 of the WHOQOL–HIV BREF (Spiritual/religion/personal beliefs) and all its facets (forgiveness and blame, concerns about the future, and death and dying) are categorized under this measurement.

Characteristics of the environment: The characteristics of the environment theoretically include all of the individual's surroundings; including the social and physical environment. Characteristics of the environment refer to factors outside of the individual which may impact biological function, symptom status, functional status, general health perceptions and overall HRQOL. They address the individual's interactions with others as a member of society. Social environmental characteristics are the interpersonal or social influences on health outcomes, including the influence of family, friends, and healthcare providers. Physical environment characteristics are those settings such as the home, neighbourhood, and workplace that influence health outcomes either positively or negatively through HIV related stigma and social support.

On the WHOQOL-HIV BREF instrument, domain 5 (Environmental) and its facets (physical safety and security; home environment, financial resources, health and social care-accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment (pollution/noise/traffic/climate) and transport were included in this measurement.

An explicit assumption of the Ferrans Conceptual Model is that understanding the relationships among these components will lead to the design of optimally effective interventions and the conceptual model could be applied to any health care discipline (Ferrans et al. 2005:366). Throughout this study, the selection of study variables, data analysis and reporting of both quantitative and qualitative results were guided by the model's components.

1.13 DEFINITIONS OF KEY TERMS

Key terms used in the study are described in this section:

Age of majority: The 'age of majority ' is a legal term for the age when a person reaches adulthood and has all of the rights and privileges of an adult. At this age, the child is considered an adult under the law and is legally responsible for their actions. In Botswana, according to the Botswana Children's Act (2009:37), the age of majority is 18 years.

Young Adult: This study defines young adults as individuals aged approximately 18-30 years and focuses primarily on this age range (Havighurst 1972:45).

Developmental tasks: A developmental task is one that arises predictably and consistently at or about a certain period in the life of the individual. Developmental tasks arise from physical maturation, social-cultural forces, and personal values and aspirations. According to human development theorists, `developmental tasks of young adulthood differ across cultures however the common critical ones include choosing a partner, establishing a family, parenting, managing a home, and establishing a career (Havighurst 1953:2).

Perinatal HIV infection: Perinatal HIV infection also referred to as vertical or mother-to-child transmission (MTCT) is the transmission of HIV infection from a woman to her child. Perinatal transmission can occur during the antenatal period, labour and delivery, or as a result of breastfeeding.

Young Adult with Perinatal HIV (YALPH): A young adult aged between 18 and 30 years with confirmed perinatal HIV infection and enrolled on ART at Botswana-Baylor Children's Clinical Centre of Excellence during the data collection period. A young adult was considered to have perinatally acquired HIV infection if his/her mother was HIV infected according to clinical records or if s/he was found to be positive during infancy or early childhood without another documented explanation for exposure.

Antiretroviral drugs (ARV): Refers to the medicines used to treat HIV.

Antiretroviral Therapy (ART): Refers to the use of a combination of three or more ARV drugs for treating HIV infection. ART involves lifelong treatment.

Treatment as Prevention: Use of ARV drugs for HIV prevention refers to the HIV prevention benefits of ARV drugs and includes ARV drugs given to the mother or infant for preventing the mother-to-child transmission of HIV (PMTCT), ARV drugs to reduce the transmission of HIV among sero-discordant couples and ARV drugs to prevent people from acquiring HIV when they are exposed; post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).

Viral Load Suppression: Refers to a viral load below the detection threshold used in Botswana (<400 copies per mL) using viral assays and unsuppressed viral load refers to the inability to achieve or maintain viral suppression below the threshold (>400copies per mL).

Health: WHO defines health as "a state of complete physical, mental, and social wellbeing and not merely the absence of disease" (WHO 1946:100).

Quality of Life: QOL of life is the person's overall satisfaction with life. WHO defines QOL as individuals' perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

Health Related Quality of Life: WHO defines HRQOL as “the functional effect of a medical condition and/or its consequent therapy upon a patient” (WHOQOL Group 1998: 551). In this study, the HRQOL was operationalized as a multi-dimensional concept that included the physical, psychological and social functioning associated with perinatally acquired HIV infection and its treatment.

Factors affecting HRQOL: The factors which had a statistically significant association with general HRQOL in the sampled YALPH.

Disability: According to the Botswana National Disability Policy (Republic of Botswana 2011:2), disability is a long-term impairment, be it physical, mental, intellectual, or sensory whether inherited or acquired which, when combined with environmental and societal barriers limits the person’s ability to function on an equal basis with others who have no impairment.

Policy: Policies are the decisions, plans, and actions that are undertaken to achieve specific health care and other goals within a society. According to WHO, health policy can achieve many things: defines a vision for the future, outlines priorities and the expected roles of different groups, and builds consensus and informs people (WHO, 2019:1).

1.14 CONCLUSION

Young adulthood is a critical period of human development. The developmental tasks of young adulthood include completing school, finding employment, leaving the parental home, marriage and parenting. YALPH have to face the challenges related to growing up with HIV infection and also confront the same challenges of young adulthood faced by other HIV negative youth. Any or all of these factors put them at risk of poor QOL. Assessments of HRQOL of YALPH is key to identifying which groups are at risk of poor or declining QOL and to inform interventions to support them. Therefore, this study aimed to assess the HRQOL of YALPH, identify the factors affecting their HRQOL and provide policy recommendations on how best to promote their HRQOL. There are many health, education, social welfare, and youth development policies and programs in Botswana that are potentially relevant to young adults HRQOL. It was important to explore how the YALPH could be supported by those programs and others to promote their HRQOL.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of this review was to identify documented information on the factors that affect the HRQOL in young adults living with perinatally acquired HIV (YALPH). The Ferrans Conceptual Model of HRQL (2005) provided the basis for the literature review. The keywords used in the search included: quality of life (QOL); health-related quality of life (HRQOL); perinatally HIV infected young adults; factors affecting HRQOL; and determinants of HRQOL. Articles were found searching Pubmed, Medline and a hand search was conducted in the Health Sciences Section at the University of the Botswana Library.

2.2 FACTORS AFFECTING HRQOL

2.2.1 Characteristics of the Individual:

2.2.1.1 Social-Demographic Factors:

Although PLWH experience the benefits of long-term use of HAART, various socio-demographic characteristics such as gender, age, education level and employment status may impact their HRQOL (Degroote, Vogelaers & Vandijck 2014:2).

Age: The relationship between HRQOL and age has been inconsistent in the literature. Some studies have reported a negative correlation between age and HRQOL showing lower HRQOL with older age (McGowan, Sherr, Rodger, Fisher, Miners, Johnson, Elford, Collins, Hart, Phillips, Speakman & Lampe 2014:1; and Mwesigire et al. 2015:7). Younger age has been associated with better mental health and physical health (Ndubuka et al. 2016:4). Other studies found a positive correlation between age and HRQOL showing higher HRQOL with older age leading to the conclusion that older people may have more established social support systems and better coping skills (Bakiano et al. 2015:3; and George, Bergin, Clarke, Courtney & Codd 2016:5). Other studies found weak or no correlations between age and HRQOL (Tesfay 2016:5; Mekuria et al. 2015:934; and Karkashadze et al. 2017:675).

Gender: The relationship between gender and HRQOL has been inconsistent in the literature. Globally, in PLWH, women consistently report poorer HRQOL than men (Tesfay et al. 2015:16; Thapa, Amatya, Pahari, Bam & Newman 2015:10; Mwesigire et al. 2015:7; and George et al. 2016:6). However, in other studies, females had a better QOL compared to males (Peltzer & Phaswana-Mafuya 2008:209; and Imam, Karim, Ferdous & Akhter, 2011:5).

The nature of gender differences in HRQOL is complex, but it is proposed that the differences may depend to a greater extent on socio-demographic or psychosocial factors rather than on the objective health status (Vo, Hoffman, Nash, El-Sadr, Tymejczyk, Gadisa, Melaku, Kulkarni, Remien & Elul 2016:1682). Women are more likely to report their unfavourable physical states than men because in many cultures, men are expected to adopt a more stoic attitude (Degroote et al. 2014:2). It has also been suggested that gender differences in HRQOL could also be due to gender differences in mental health as mood disorders, anxiety disorders and psychosomatic disorders are more prevalent in females, possibly contributing to the HRQOL difference (Tran, Ohinmaa & Nguyen 2012:187; and Vidrine, Amick III, Gritz & Arduino 2005:930). The higher incidence of depression and psychological disturbances in women living with HIV has been one of the reasons for the gender differences in the literature (Degroote et al. 2014:2).

2.2.1.2 Socio-economic status:

Studies have reported that education, employment and financial resources are closely interrelated and they impact the HRQOL.

Level of Education: Generally, education, an indicator of socioeconomic status, has been shown to influence HRQOL. Having a higher level of education has been identified as a factor for improved HRQOL among PLWH (Mafirakureva, Dzingirai, Postma, Hulst & Khoza 2016:909; and George et al. 2016:3). PLWH with a higher level of education have a significantly higher perceived HRQOL, possibly due to better access to information about their treatment and disease, access to health services which led to better coping attitudes towards the disease and improved HRQOL (Karkashadze 2017:675; Mafirakureva et al. 2016:909; and Mbalinda et al. 2015:7).

Additionally, educated individuals tend to have the income to buy a variety of foods needed to diversify diet and positively impact nutrition status. A study by Thapa et al. (2015:10) in Nepal found education status to be significantly associated with the nutritional status of PLWH. In that study, the PLWH who were illiterate were almost 2.5 times more likely to be undernourished than those who were literate. Education has also been found to promote the adoption of positive behaviors like good sanitation and appropriate food choices (Tesfaye et al. 2016:4; and Thapa et al. 2015:10).

In perinatally HIV infected youth, educational performance and attainment can be impacted by non-cognitive factors such as poor general health, low parental or caregiver educational attainment but also possibly due to HIV-related cognitive deficits (Ene, Franklin, Burlacu, Luca, Blagosov, Alexander, Umlauf, Grant, Duiculescu, Achim & Marcotte 2014:496; Allsop, Ashby, Fidler, Foster, Garvey, Paramesparan, Taylor-Robinson, Wan & Winston 2014:81; and Willen, Cuadra, Arheart, Post & Govind 2016:387). An array of neurocognitive deficits have been described among YALPH including executive functioning deficits, memory problems and language development and functioning problems (Nichols, Chernoff, Malee, et al. 2016:15; Sirois, Chernoff & Malee 2016:24; and Ene et al. 2014:496).

For instance, a prospective study on YALPH using a neuropsychological test battery found higher cognitive impairment prevalence (59.1%) compared to age and gender-matched peers (10%). The impairment rate remained significantly higher even when the groups were matched on the educational level (38.7%) for the HIV positive group vs. 10% for the HIV negative controls ($p=0.025$). This rate of impairment was notable given that most of the respondents were on ART, had undetectable VL and good immunological status (Ene et al. 2014:496). Resultantly it has been noted that cognitive remediation interventions may be helpful in YALPH, as has been demonstrated in adults with other brain insults (Weber, Blackstone & Woods 2013:81; and Abrams et al. 2018:8).

Employment status: Studies have demonstrated a correlation between employment and HRQOL showing that employed PLWH have better overall QOL than unemployed PLWH (Mekuria et al. 2015:934; Ndubuka et al. 2016:6; Mafirakureva et al. 2016:904; and George et al. 2015:5). The exact association between employment and HRQL has not been proven, however, it is suggested that probably this is a bi-

directional relationship: good HRQOL could be a requirement to be able to work or work could be a source of well-being (Degroote et al. 2014:10; and Mafirakureva et al. 2016:904).

Additionally, employment may provide resources, which buffer the effects of the stress of HIV infection and thus serves to maintain a sense of normalcy and QOL (Mekuria et al. 2015:937). It also has been suggested that besides financial benefits, employment constitutes a big part of the daily life of people and it can provide structure, a social support network, role identity and meaning (Degroote et al. 2014:10; and Mekuria et al. 2015:937).

Employment and income have also been associated with the ability to obtain sufficient nutritious food. Food insecurity and malnutrition have a negative association with HRQOL among PLWH including those on ART (Mekuria et al. 2015:937; Thapa et al. 2015:7; George et al. 2016:5; and Tesfay et al. 2016:4). Additionally, there is evidence that food insecurity increases the risk of mental health problems among young adults and that efforts to reduce food insecurity could help prevent the presence of mental health problems in that population (Tesfay et al. 2016:4; and Thapa et al. 2015:10).

2.2.2 Biological Function:

In PLWH, clinically meaningful biological/physiological factors that serve as indicators of disease status and have been found to affect HRQOL include VL, CD4 Cell Count and Body Mass Index (BMI).

Virological and immunological status (Viral Load and CD4 Cell Count):

Viral Load (VL): Numerous researches conducted during the HAART era have shown that having a lower VL positively impacts the HRQOL of PLWH including the overall, physical and mental health (Bucciardini 2014:176). This association between VL and HRQOL indicators shows that these can be direct proxies of each other and that the VL alone may be adequate eligibility criteria for HRQOL interventions. However, other studies found weak or no independent association between VL and HRQOL indicators (Mekuria 2015:934; and George et al. 2016:1).

Additionally, large cross-sectional studies comparing the HRQOL of PLWH and the general population showed that PLWH have significantly lower HRQOL than do the general population, despite most HIV positive individuals in the studies being virologically and immunologically stable (Do, Rosenberg & Sullivan 2014:13; and Miners, Phillips, Kreif, Rodger, Speakman, Fisher, Anderson, Collins, Hart, Sherr & Lampe 2014:32). Those studies provide evidence that other non-biological factors such as psychological and behavioural factors need to be explored in promoting HRQOL.

CD4 Cell Count: The association between CD4 cell count and HRQOL is inconsistent in the literature. Some studies have found a strong relationship between HRQOL and CD4 cell count of PLWH leading to the conclusion that practical interventions to improve CD4 cell count are likely to also improve HRQOL (Thapa et al. 2015:7; Nglazi et al. 2014:8; and Karkashadze, Gates, Chkhartishvili, DeHovitz & Tsertsvadze 2017:675). A study conducted by Gowda et al. (2013:265) on adults aged 18 years and above in Mysore District, India, using the WHOQOL-HIV BREF instrument, showed a significant positive correlation between CD4 cell count and all the four domains of HRQOL with the social domain showing the highest positive correlation with CD4 cell count. However, other researchers found weak or no correlations between CD4 cell count and HRQOL (Mafirakureva et al. 2016:911; Folasire, Folasire & Sanusi 2015:412; Mwesigire et al. 2015:7; George et al. 2016:19; Cronje, Williams, Steenkamp, Venter & Elkonin 2017:632; and Bucciardini et al. 2014: 176).

The authors have cited several possible reasons that the relationship between CD4 cell count and VL and HRQOL was not substantiated. It is suggested that HIV patients may be asymptomatic even when CD4 cell counts are low and VL are high, and HRQOL may not be responsive to these clinical indicators until the illness is more advanced (Mekuria et al. 2015:934; and Nobre, Pereira, Roine, Sintonen & Sutinen 2017:1074.) There is also evidence to suggest patients may emphasize psychological and social functioning rather than physical functioning on HRQOL instruments (Mwesigire et al. 2015:7; and Nobre et al. 2017:1074). The persons with lower CD4 cell count and high VL may have developed better coping skills to deal with the emotional and social aspects of HIV. It is also suggested that over time, PLWH develop other perceptions and expectations about HRQOL and may consider their health status acceptable (Mwesigire et al. 2015:7; and Nobre et al. 2017:1074).

Hence, the weak to no association between the biomedical markers of CD4 cell count, VL and HRQOL indicators showed that these cannot be direct proxies of each other and that the CD4 cell count and VL alone may be inadequate eligibility criteria for social support. Hence the results of those studies signify the need to combine ART with psycho-social and other interventions when promoting HRQOL.

Body Mass Index (BMI): According to WHO, BMI is a measure for indicating nutritional status in adults. BMI is defined as a person's weight in kilograms divided by the square of the person's height in meters (kg/m^2) that applies to adult men and women. Studies conducted in many countries have shown a statistically significant association between BMI above and below normal and decreased HRQOL (Folasire et al. 2015:419; Thapa et al. 2015:10; Tesfaye et al. 2016:4; and Dey, Gmel & Mohler-Kuo 2013:13). A study to assess the association between BMI (from being underweight through obesity) and HRQOL in young Swiss men with a mean age of 19.9 years in a population-based sample showed that being overweight or obese was associated with reduced physical HRQOL, whereas being underweight predicted reduced mental HRQOL. However, the study also showed that obese men had better mental HRQOL than men of normal weight even though this effect was relatively small (Dey et al. 2013:5).

In addition, a study conducted in Nigeria to assess the relationship between nutritional status with domains of QOL of PLWH showed that BMI had a significant positive association with the psychological HRQOL domain (Folasire et al. 2015: 412). And a study conducted in Nepal to assess associations between nutritional status and HRQOL of PLWH using BMI as an indicator for nutritional status found BMI was significantly correlated with three domains of HRQOL that is Psychological, Social, and Environmental domains (Thapa et al. 2015:10). The results of those studies indicate that nutrition interventions should form an integral part of HIV care programs and that interventions should aim to preserve or re-establish normal weight. Preventing malnutrition and obesity are important in managing HIV.

2.2.3 Characteristics of the Environment:

Characteristics of the environment such as social support and HIV related stigma may influence all aspects of a patient's overall health and play an important role in the HRQOL of PLWH.

HIV-related Stigma: Stigma has been described as a type of "spoiled identity" that occurs when a person or group possesses a particular attribute that is viewed by others in society as an "undesirable difference" resulting in social sanctions against those who possess that attribute (Goffman 1963:3). Specific to PLWH, HIV-related stigma has been defined as socially shared attitudes, beliefs, or actions that promote and perpetuate the devalued status of people living with or affected by HIV (Florom-Smith & De Santis 2012:154). Stigma has further been conceptualized as a psychosocial stressor that can take three distinct mechanisms through which HIV-positive individuals experience stigma: enacted, anticipated and internalized stigma (Earnshaw, Smith, Chaudoir, Amico & Copenhaver 2013:1787). Enacted stigma refers to experiences of discrimination or perceptions of being treated differently as a result of being HIV infected. And anticipated stigma is the extent to which PLWH perceive or expect prejudice against themselves. Internalized stigma refers to when an HIV-positive person endorses negative attitudes associated with HIV and accepts them as applicable to him or herself (Earnshaw et al. 2013:1787).

Stigma as an environmental factor has been found to have a consistently negative effect on HRQOL of PLWH (Tesfay et al. 2015:15, Mekuria et al. 2015:34; and Madiba & Mokgatlhe 2016:8). Stigma influences the HRQOL of YALPH by undermining ART adherence leading to poor health outcomes (Pantelic, Boyes, Cluver & Thabeng 2016:207; Huynh, Kinsler, Cunningham & Sayles 2013:1179; Sweeney & Vanable 2016:29; and Turan, Atkins, Kempf, Clay, Raper & Mugavero 2017:198). Fear of stigma also affects the HRQOL of YALPH by reducing social support resources leading to decreased general psychological health (Martines, Harper, Carleton, Hosek, Bojan, Clum, Ellen & ATN 2012:108).

In YALPH, HIV-related stigma often results in avoidance of socialization opportunities, including support groups and event programming, as young adults with HIV fear inadvertent disclosure, discrimination or rejection (Mutumba, Bauermeister, Musiime, Byaruhanga, Francis, Snow & Tsai 2015:86; Bekele, Rourke, Tucker,

Greene, Sobota, Koornstra & Watson 2013:337; and French, Greef, Watson & Doak 2014:905). Because of this, young adults with HIV who experience or perceive stigma may have fewer opportunities to communicate with peers who could provide coping support.

In a study comparing the coping strategies of individuals with HIV, active coping was associated with decreased internalized stigma and depression along with increased self-esteem, health literacy, and social support. Likewise, avoidance coping is associated with increased internalized stigma, increased depression, lower levels of self-esteem and lower HIV literacy (Kotzé, Visser, Makin, Sikkema & Forsyth 2013: 498). On the other hand, social support for young adults with HIV has been shown to promote positive health behaviours such as medication adherence (Sweeney & Vanable 2016:29; and Turan et al. 2017:198). Therefore, efforts to improve the HRQOL of YALPH need to target stigma among this population.

Social Support: Social support is an environmental factor that has been found to have a positive impact on HRQOL (Degroote et al. 2014:10; and Andrinopoulos, Clum, Murphy, Harper, Perez & Xu 2011:367). Social support is generally defined as "the perception or experience that one is loved and cared for by others, esteemed and valued and part of a social network of mutual assistance and obligations" (Taylor 2007:145). In consideration of that definition, and in line with the developmental tasks of this phase of life, young adulthood is associated with a wide range of social relationships and networks that emanate from families of origin, a network of peers, places of work, romantic relationships and community members which have direct and indirect impacts on the health and HRQOL of young adults (Shanahan 2000: 667).

According to Caplan (1976:44) much or most of the beneficial health effects of social relationships are due to their buffering properties in the presence of stress, hence the term social support. Accordingly, Cohen and Willis (2004:94) present the "main effect" versus "the stress buffering" hypothesis. The "main effects" hypothesis states that the more social support an individual has, the better the QOL regardless of the person's level of stress. The "stress buffering hypothesis", however, states that the relation of social support to QOL depends upon an individual's level of stress. If there is no stress, or little stress, social support is unrelated to QOL. Under conditions of high

stress, that social support serves as a buffer against the adverse effects of that stressor.

House, Landis and Umberson (1988: 293-318) outlined four broad types of social support that are extensively referenced in the literature:

1. Informational Support involves the provision of information, education, or guidance for use in managing personal and health-related problems.
2. Instrumental Support or tangible support involves the provision of tangible assistance, in the form of financial aid, material goods, time, food insecurity and microcredit loan programs or any direct help.
3. Emotional Support involves the provision of empathy, affection, love, trust, encouragement, listening, and care from members of an individuals' social network.
4. Appraisal Support also referred to as affiliative support and social integration) involves the number of social relationships an individual has with others that have mutual interests. This type of support also provides affirmation and feedback.

Social support is a protective factor for improved HRQOL (Degroote et al. 2014: 10; Andrinopoulos et al. 2011: 367; and Chen, Han, Liao, Dai, Liu, Chen & Peng 2015:6). People with more social support also have fewer depressive symptoms (Xiaowen, Guangping, Ling, Jiarui, Xiumin, Zhaoqin, Hongzhuan, Yuyan, Liyuan & Lin 2018: 1147; and Seffren, Familiar, Murray, Augustinavicius, Boivin, Nakasujja, Opoka & Bass 2018: 888). In a study conducted in Nepal to assess the relationship between satisfaction with social support, hope and HRQOL among PLWH, respondents' overall satisfaction with their social support and hope was significantly and positively correlated with all domains of HRQOL measured (that is physical functioning, psychological functioning, social relationships, environmental functioning, and global functioning). The results also showed that satisfaction from informational and tangible support was a better predictor of HRQOL as compared to satisfaction with emotional support (George et al. 2016:12).

Developmentally, young adulthood is centered on peer relationships and on the ability to communicate and connect with those who have similar interests including peers, classmates, workmates, neighbours, community members, and sexual and romantic partners (Sameroff 2010: 6). Because socialization is so vital to young adults, peer relationships have the potential to positively influence adjustment to chronic illness (Sameroff 2010: 15).

Social support for YALPH has been shown to promote positive adjustment to chronic illness and increase positive health behaviours such as medication adherence (Huynh et al. 2013:1179). However, HIV-related stigma often results in avoidance of socialization opportunities due to fear of inadvertent disclosure, discrimination, or rejection (Bekele et al. 2014: 905; and Earnshaw et al. 2018:44). Because of this, young adults with HIV have fewer opportunities to communicate with peers who could provide support. This implies that regular screening of HIV-positive youth for social support needs and identification of sources for social support should be part of the care and promotion of HRQOL.

Self-Disclosure of HIV Status: In the context of PLWH, self-disclosure describes the process whereby the HIV-positive person discloses their status to others. HIV disclosure can be seen as a complex, multidimensional process of deciding on whom to inform about one's HIV serostatus, why, when, where, and how to disclose (Eustace & Ilagan 2010: 2094).

Research has demonstrated the link between disclosure and HRQOL. Self-disclosure of HIV serostatus by the youth who are HIV-positive has been considered an important objective for preventing HIV transmission and increased HRQOL through enhancement of social support, reduced anxiety and depression (Hult, Wrubel, Branstrom, Acree & Maskowitz 2012:181; and Thoth, Tucker, Leahy & Stewart 2014:276). Additionally, HRQOL can be improved as disclosure to family and friends can lead to increased social support, which can facilitate adherence to HIV treatment that, in turn, improves physical health and lowers the presence of symptoms (Thoth, Rucker, Leahy & Stewart 2014: 276; and Nglazi et al. 2014:6).

Disclosure to sexual partners supports risk reduction behaviours that ultimately decrease transmission of HIV, while also facilitating access to prevention, care and treatment services (Thoth et al. 2014:286). However, as with older adults, disclosure to family, friends and sexual partners may be difficult for YALPH. Fear of stigma and the desire to retain a sense of control over who knows one's HIV status remains the most cited barrier to disclosure in youths living with HIV (Madiba & Mokgatlhe 2016:8; and Weintraub, Mellins, Warne, Dolezal, Elkington, Bucek, Leu, Bamji, Wiznia & Abrams 2018:1).

2.2.4 Functional Status:

Functional status is one's ability to participate in day-to-day activities. According to Wilson and Cleary (1995:62), there are four domains of functional status: physical function, social function, role function and psychological function. Functional status includes physical activity, energy levels, and performance of everyday tasks. The Functional status has been measured as both a predictor variable and outcome measurement in the HRQOL of PLWH. Largely, PLWH who are treated with ART have a near-normal life expectancy and maintain high functional status and independence (Degroot 2014:4). Higher levels of functioning indicate better overall general health. Physical functioning refers to everyday physical activities, while social functioning represents everyday social activities.

According to Shriharsha and Rentala (2019:1011) many HIV infected people may face challenges to attend to daily tasks of living, participate in heavy physical activities, or have sufficient energy to participate in active social life while managing HIV/AIDS. PLWH who had better overall functioning (Phaladze, Human, Dlamini, Hulela, Hadebe, Sukati, Makoae, Seboni, Moleko & Holzemer 2005: 120), and who participated in frequent physical activity, had a higher overall HRQOL than their less active counterparts (Frantz & Murenzi 2013:116). In a study of 98 HIV-positive Nepali women, both social functioning and physical functioning had a significant relationship with satisfaction with life (Eller & Mahat 2007:17). Physical functioning was also positively correlated with HRQOL in that PLWH who participated in more frequent physical activity also showed higher overall general health perceptions (Frantz & Murenzi 2013: 116).

ART Adherence: Medication adherence can affect the functional status of PLWH. According to the WHO, medication adherence is "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO 2003:4). In the case of HAART, strict or near-perfect adherence (≥95%) is a requirement for optimal therapeutic outcomes (WHO 2006:28). Furthermore, perfect adherence to HAART is critical because of the available evidence that a suppressed HIV VL greatly reduces the risk of onward transmission of HIV to sexual partners (Davey et al. 2018:6; and Cohen, Chen & McCauley 2015:493).

Medication non-adherence is commonly reported among YALPH and is associated with reduced likelihood of virologic suppression, increased risk of developing virological failure and disease progression which reduces patients' QOL (Ehlers & Tshisuyi 2015:4; Davey, Abrahams, Fenberg & Darkoh 2018:6; and Vagiri, Meyer, Godman & Gous 2018:121). Poor ART adherence and increased odds of achieving VL suppression in YALPH have been associated with a host of developmental, social, individual and contextual factors (Hawkins, Evangeli, Sturgeon, Le Prevost & Judd 2016: 68; and Bucek et al. 2018:673). Additionally, longitudinal studies have shown that YALPH are vulnerable to psychiatric disorders putting them at high risk of poor medication adherence, viremia and poor health outcomes (Kacanek et al. 2015: 1227; and Abrams et al. 2018:4).

Studies of adherence in PLWH in Botswana showed almost similar challenges to adherence. A study to assess barriers to adherence among non-adherent adolescents and young adults living with HIV showed low outcome expectancy, treatment fatigue, mental health and substance use problems and mismatches between desired and received social support as reasons for poor adherence (Yang, Mphele, Moshashane, Bula, Chapman, Pettitt, Tshume, Okatch, Marukutira, Anabwani & Lowenthal 2018:224). A study by Ndubuka et al. (2016:1) found reasons for discontinuing ART included transport challenges (22.4%), feeling better (21.4%), running out of pills (11.2%), depression (8.2%), lack of care and/or support (8.2%), failure to understand instructions (7.7%), medications' side effects (6.1%) and alcohol abuse (3.1%) were the reasons for poor adherence.

In another study conducted in Botswana, Ehlers and Tshisuyi (2015:7) found barriers to ART adherence to include forgetting to take the medicines, transportation costs to and from ART clinics, as well as income lost because of absence from work to visit ART clinics. The study showed the motivators for adherence to ART to include disclosure of one's HIV-positive status to more than one person, self-efficacy and availability of adherence partners. Results of those studies indicate the need to address environmental and individual factors that affect adherence and VL suppression which leads to better HRQOL of YALPH (Umar, Levy, Bailey, et. al. 2019:1; and Shubber, Mills, Nachega, Vreeman, Freitas, Bock, et al. 2016: 1).

Several studies in various settings internationally show a correlation between HRQOL and adherence to ART (Sophie, Dirk & Dominique 2014:40). The relationship is conceptualized to be bi-directional, with adherence to ART influencing one's HRQOL either for the better or worse or with HRQOL influencing one's ability or willingness to adhere to ART (Nglazi, West, Dave, Levitt & Lambert 2014:8; Degroote, Volgelaers & Vandijck 2014:40; Vagiri, Meyer, Godman & Gous 2018:121; Mataranyika, Kibuule, Kalemera, Kaura, Godman, Rennie 2017:55; and Monteiro, Fabiana, Canavarro & Pereira 2016: 92). A study conducted in South Africa to assess the relationship between HRQOL and adherence to HAART found that patients who reported adherence of ≥95% reported better HRQOL compared to those who reported adherence of <95% over a period of 12 months. The results led the authors to conclude that adherence to HAART potentially improves HRQOL (Vagiri et al. 2018: 121). Those studies highlight the need to enhance ART adherence to improve the HRQOL of YALPH.

However, although ART can result in better clinical outcomes and potentially improved HRQOL, the side effects of ART can negatively influence HRQOL. ARV drugs pose a challenge for HRQOL as they can cause significant side effects in addition to the potential for drug toxicity and interaction (Gaida, Truter, Grobler, Kotze & Goldman 2016:377; Kalemeera, Mbago, Mubita, Naikaku, Gaida & Goldman 2016: 782; Mataranyika, Kibuule, Kalemeera, Kaura, Godman & Rennie 2017:49). Medication side effects related body alterations such as lipodystrophy, skin infections and scars, bring not only physical discomfort but are also associated with stigma and can diminish HRQOL (Degroot et al. 2014: 4).

2.2.5 Symptoms Status:

Symptom status is described theoretically as any psychophysical, emotional or cognitive state that influences the individual. Symptoms are the expression of a disease on a patient's physiological and psychological status (Ferrans et al. 2005: 339). Symptoms can be either physical or mental. Studies have reported symptoms of HIV to be independently associated with HRQOL (Olson, Vincent, Meyer, Kershaw, Sikkema, Heckman & Hansen 2019: 3313; Degroote et al. 2014:4; George et al. 2016: 9; and Tesfaye 2016:5). The presence of HIV symptoms affects functionality and life satisfaction leading to impaired QOL. In a study in Ireland by George et al. (2016: 9) it was shown that having symptoms of HIV and comorbidities were the most significant clinical variables independently associated with HRQOL. Additionally, there are unfavourable effects of HIV stigma, discrimination, disclosure and other psychosocial issues. As a result, a high prevalence of psychological and psychiatric symptoms has been identified in HIV infected youth in care (Brown, Whiteley, Harper, Nichols & Nieves 2015: 212; and Abrams et al. 2018:4).

In a study of 743 men and women in sub-Saharan Africa including Botswana, patients who expressed more severe HIV-related symptom intensity (measured by the Revised Sign and Symptom Checklist for Persons with HIV Disease) had lower overall satisfaction with life (Phaladze 2005:120). In a study by Kovacevic (2006: 82) using the WHOQOL-HIV BREF, ratings of QOL differed across health status and "currently ill" status. Subjects who perceived themselves as not ill and rated their health status as better reported better QOL for all the measured QOL domains.

In a longitudinal study conducted in the USA to assess the association between HRQOL and symptoms over time in HIV infected persons in a national representative sample of adults in the USA, the results showed that controlling for baseline symptoms and HRQOL, each additional symptom at follow-up was associated with worsened overall health and worsened overall QOL (Lorenz, Cunningham, Spritzer & Hays (2006: 951) quoted in Degroote et al. 2014:3). The results of the study showed that respondents who had fewer total symptoms and higher overall QOL at baseline had higher QOL at the end of the study. In the same study, patients who had worsening symptoms over time showed significant decreases in overall health (Lorenz et al. 2006: 951 quoted in Degroote et al. 2014:3).

Despite the significant improvement in HRQOL due to reduced symptoms, studies have consistently shown that the side effects of ART have significant effects on HRQOL (Astuti & Maggiolo 2014:1; and Lungren et al. 2015: 808). Having few ART related side-effects contributed to normal physical and mental health (Lungren et al. 2015: 808). For example, lipodystrophy which is a highly visible symptom is highly stigmatizing and adversely impacts the self-image and QOL of PLWH (Verolet et al. 2015: 5; and George et al. 2016:9).

Additionally, and increasingly, the evidence is emerging in the literature on the risk of non-communicable diseases and metabolic complications of ART in YALPH (Lipshultz, Miller, Wilkinson, Scott, Somarriba & Cochran 2013:2; Dapena, Jiménez, Noguera-Julian, 2012: 529; and Vigano, Cerini, Pattarino, Fason & Zuccotti 2010: 431). Perinatally infected youth will have prolonged exposure to therapy throughout various stages of growth and development, receive multiple drug regimens as they age, and are at high risk for metabolic complications. While these youths are still too young to have experienced cardiovascular and other metabolic outcomes of HIV and ART, perinatally infected youth are at increased risk as they enter the third and fourth decades of life (Lipshultz et al. 2013:2; Blázquez, Ramos-Amador, Saínz 2015:6; and Vigano et al. 2010: 431).

Those authors emphasize the need for routine metabolic and NCD evaluation for perinatally infected youth as they age into adulthood. The authors note that developing effective strategies to monitor, prevent and manage NCD and metabolic complications of therapy in perinatally infected youth will be important. Therefore, alleviating symptoms of HIV, preventing co-morbid conditions, preventing and managing NCDs and metabolic complications of ART is important in improving the HRQOL of PLWH. Additionally, providing access to less toxic drug combinations must be a high priority for policymakers and health care professionals involved in treating HIV infection globally.

Mental Health Disorders: Symptom status can also include mental health disorders. Mental health disorders are clinically significant behavioural or psychological impairment(s) of an individual's normal cognitive, emotional or behavioural functioning associated with present distress and caused by physiological or psychological factors. Research conducted in various countries suggests that youths with perinatal HIV are at high risk for mental health disorders including depressive

disorders, anxiety disorders, substance use issues, post-traumatic stress disorders as well as psychiatric symptoms compared to their HIV negative peers (Kacanek, Angelidou, Williams, Chernoff, Gadow & Nachman 2015:1235; and Abrams, Mellins, Bucek, Dolezal, Raymond, Wiznia, Jurgrau, Bamji, Leu & Ng 2018:4). For example, data from the Child and Adolescent Self-Awareness and Health Study (CASAH) a longitudinal behavioural health cohort study of YALPH and perinatally HIV exposed but uninfected young adults (PHEUYAs) in New York City showed a high prevalence of selected psychiatric disorders (27%), including mood (11%), anxiety (22%) and substance use (28%). Those psychiatric diagnoses were predictive of viremia over the ensuing 2-3 years (Abrams et al. 2018:1). The high prevalence of mental health disorders in YALPH is associated with stressful life experiences such as childhood trauma, serious illness and hospitalization, parental death, poverty, abuse, HIV stigma, as well as other problems of longstanding HIV through childhood and adolescence (Kacanek et al. 2015:1227; and Abrams et al. 2018: 4).

Additionally, research suggests that perinatal HIV infection and the use of ARV at a young age may influence neurodevelopment and may be associated with an increased risk of mental disorders. A systematic review of existing literature regarding neurodevelopment in perinatally HIV-infected children conducted by Laughton, Cornell, Boivin & Van-Rie (2013:4) showed that the neuropathology caused by HIV affects the basal ganglia, and cerebral white matter and that neuronal loss is prominent in prefrontal cortex regions. The degeneration in the brain was associated with challenges in complex mental processing among HIV-infected children. The study suggests that those changes were a contributing factor for the higher prevalence of psychiatric and mental problems for perinatally HIV infected youth (Laughton et al. 2013:4).

Mental health disorders among perinatally HIV infected youth have been associated with poor ART adherence and lack of virologic control (Nell & Kagee 2011:1360; Kacanek et al. 2015:1227; Abrams et al. 2018:1; and Bucek et al. 2016:673). According to a systematic review of literature conducted by Nell & Kagee (2011: 1360), depressive symptoms such as low motivation, poor concentration, sleep disturbance, psychomotor retardation, fatigue, loss of energy and feelings of worthlessness, all directly contribute to patients lacking the ability and motivation to attend medical appointments and maintain treatment schedules. Patients with depression were three times more likely to be non-adherent to treatment than those

without mental illness (Nell & Kagee 2011:1360). Additionally, cohort studies in the USA found psychiatric diagnoses were predictive of viremia and poor health outcomes (Kacanek et al. 2015: 1227; and Abrams et al. 2018:1).

PLWH who are depressed or anxious report reduced HRQOL (Mekuria, Spranges, Prins, Yalew & Nieuwkerk 2015:934; Mutabazi-Mwesigire, Katamba, Martin, Seeley & Wu 2015:12; and Verolet, Delhumeau-Cartier, Sartori, Toma, Zawadynski, Becker, Bernasconi, Trellu & Calmy 2015: 5). A study conducted by Mekuria with adults in Ethiopia found a higher level of depressive-symptoms was strongly and consistently associated with a lower HRQOL, both in terms of the magnitude of the relationship and in the number of HRQOL domains associated with it (Mekuria et al. 2015:943).

Therefore, assessing and treating specific categories of mental health and substance abuse problems may enhance efforts to improve ART adherence, prevent poor health outcomes and improve HRQOL in YALPH, who are especially vulnerable due to their very challenging circumstances (Abrams et al. 2018:3). Previous studies have demonstrated that depression treatments have been successful in improving ARV adherence among PLWH. Some observational studies that analyzed retrospective records identified that higher ARV refill adherence was associated with anti-depressant prescription and anti-depressant prescription refill adherence (Pence, Gaynes, Williams, Modi, Adams, Quinlivan & Mugavero 2012: 828; and Abrams et al. 2018:1).

Thus, alleviating symptoms of HIV and preventing comorbid conditions is important in improving the HRQOL of PLWH. Additionally, providing access to less toxic drug combinations must be a high priority for policymakers and health care professionals involved in treating HIV infection globally.

2.2.6 General Health Perceptions:

According to the Ferrans Conceptual Model of HRQOL, general health perceptions are defined as the individual's perception of the state of their health, based on the integration of biological/physiologic factors, symptom status, and functional status combined with the effect of the particular disease or organ state on the individual (Ferrans et al. 2005:339). General health perceptions are a combination of biological function, symptom status, and functional status and are unique to each individual (Ferrans et al. 2005:339).

Health is one of the most important factors affecting QOL and the individual's subjective assessment of their health is an important element of their general QOL (WHO 1946:100). Therefore, better general health perceptions reflect higher overall health as perceived by the individual. Various studies have shown that patients' self-appraisal of their health significantly determined their QOL, with lower QOL recorded among those who perceived themselves as ill (Virolet et al. 2015:6; Degroote et al. 2014:6; and George et al. 2015:12). As a result of this association, researchers have consistently recommended comprehensive and consistent counselling and education for PLWH on their disease state (Bello & Bello 2013:116; and Tesfay et al. 2015:6).

2.3 CONCLUSION

This literature review demonstrates that being on ART alone does not guarantee HRQOL. Many other individual characteristics, environmental characteristics, psychosocial variables, and biological endpoints are responsible for changes in HRQOL. However, there is also evidence in the literature that many of the predictors of lower HRQOL among YALPH such as unemployment, mental health problems, stigma, limited social support, poor coping skills, low CD4 cell count, high VL and malnutrition are potentially modifiable risk factors that can be effectively targeted for policy and interventions. With appropriate treatment and management of HIV symptoms, medication side effects and other illnesses, clinicians can help improve the HRQOL of YALPH. In addition, this literature review has provided evidence that active social support from peers, family and other sources, can be an effective way to improve the mental health of the YALPH and ultimately affect their HRQOL.

Generally, there was limited literature on YALPH as a distinct population. Many published studies covered a mix of behaviourally and perinatally HIV infected young adults. In some studies, young adults were grouped with adolescents as perinatally HIV infected youth (10-24 years) or with all adults (>18 years). Hence, this literature review references some studies which include adolescents and or PLWH in general. In addition, there were limited publications on young adults and HIV/AIDS in the African region. A lot of the research on young adults had been conducted in Western Europe and North America, with a focus on behaviourally infected young adults. This study will therefore advance current research literature by presenting descriptive data of the HRQOL of YALPH an important group that is not well represented in explorations of HRQOL among PLWH.

CHAPTER THREE

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

The purpose of this chapter is to provide a comprehensive description of the research design and the methods used to achieve the purpose and objectives of the study as well as to answer the research questions. In this chapter, the research methods, the respondents of the research and sampling techniques, data collection instruments and methods adopted, data analysis methods, ethical considerations and the process used to achieve rigor and trustworthiness are presented.

3.2 RESEARCH DESIGN

A mixed methods approach combining qualitative and quantitative data collection was used. The use of multiple approaches and sources of data/information enabled the triangulation and validation of information for robust and reliable conclusions.

Methodologists Creswell & Plano-Clark (2011:45) describe mixed methods as an approach that focuses on collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies. The strength of mixed methods is that when combined, quantitative and qualitative methods complement each other and allow for more robust analysis, taking advantage of the strengths of each while reducing the weaknesses that would be associated with using each approach by itself (Creswell & Plano-Clark 2011:45; and Kaur 2016: 94). In addition, mixed methods provide a more complete and comprehensive understanding of the research problem through triangulation and complementarity (Kaur 2016:94; Burch & Heinrich 2016:44; and Noble & Smith (2015:204).

The authors (Johnson & Christensen 2012:439), state that: “triangulation provides convergence and corroboration of results from different methods while studying the same phenomenon. Complementarity provides elaboration, enhancement, illustration

and clarification of results from one method to another. Overlaps and different facets of a phenomenon can thus be understood."

According to Halcom & Hickman (2015:45), a researcher "can use different types of triangulation to provide completeness of the investigation and confirm findings. Types of triangulation strategies are: "(1) data triangulation that is the use of data collected at different times, data collected from more than one site and data collected from more than one level of respondents; (2) methodological triangulation using more than one method of data collection; (3) theory triangulation by use of more than one theory in the analysis of the same data; and (4) investigator triangulation - when different investigators with different backgrounds and expertise work together; or (5) a combination of all strategies"

According to Amgalan, Shin, Lee, Badamdorj & Yoon (2019:229); and Subedi (2016:571), data collection using the mixed methods may be done with a focus on time orientation, which could be: a) Concurrent that is data collection using qualitative and quantitative methods is conducted at the same point in time. b) In a sequence whereby one phase of data collection is followed by another for results from an initial phase to inform a subsequent phase. In sequential explanatory design, collection and analysis of quantitative data is followed by collection and analysis of qualitative data. Oftentimes, the sequential explanatory design is used to help explain, interpret or contextualize quantitative findings (Subedi 2016:571). On the other hand, in sequential exploratory design, qualitative data collection and analysis is followed by quantitative data collection and analysis, and the findings are integrated during the interpretation of the study findings (Amgalan et al. 2019:229).

In this study, sequential explanatory design was used whereby the quantitative phase was completed and then followed by the qualitative phase. The first phase was quantitative data collection and analysis using the WHOQOL-HIV BREF instrument and medical records review. The second phase was qualitative and explanatory using in-depth interviews with a purposefully selected sub-sample from those who completed the WHOQOL-HIV BREF survey. The quantitative phase of the study focused primarily on identifying the predictive factors of HRQOL among YALPH. The

results were used to develop and refine the in-depth interview questions and to inform the selection of respondents of the second phase. Significant results from the quantitative phase including trends and associations derived from the descriptive analysis, bivariate and multivariate analyses were explored through in-depth interviews. Therefore, the role of the qualitative phase was to collect descriptive information and help interpret the statistical results obtained in the quantitative phase.

An important dimension of mixed methods is the “point of interface” or the point where data mixing or integration occurs, that is during data collection, during data analysis, and/or during data interpretation and reporting (Kaur 2016:94; Amgalan et al. 2019:229; Guetterman, Fetters & Creswell 2015:556; Fetters & Freshwater 2015:116; Halcomb & Hickman (2015:4).

Integration in this study occurred at two levels: 1) first analyzing quantitative data generated by the WHOQOL-HIV BREF survey and medical records review and then using the information to inform subsequent qualitative data collection through in-depth interviews (developing interview questions and identification of respondents to interview); and 2) linking the quantitative data in the form of numeric information with qualitative data in the form of narrative quotes and reporting the results of the entire study together in the results section and the discussion section of the study. Thus, reporting first the quantitative statistical results followed by qualitative results that support or refute the quantitative results as shown in Figure 3.1

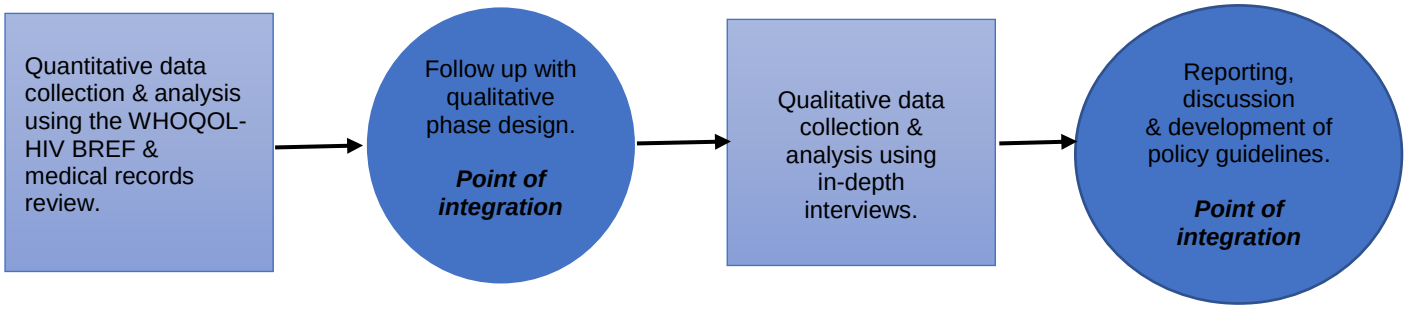

Figure 3.1: Mixed Methods Points of Integration

3.2.1 Quantitative and Qualitative Research Methods:

This section describes the nature of qualitative and quantitative research including the advantages and disadvantages of the methods.

3.2.1.1 The Nature of Quantitative Research:

As applied to this study, the quantitative approach used the WHOQOL-HIV BREF instrument and medical records review form to capture numerical data which was used to describe the social-demographic characteristics of the sample; and to identify the factors which demonstrated statistically significant predictive power for HRQOL in the YALPH.

Quantitative research is used to quantify a phenomenon by way of generating statistical data or data that can be turned into useable statistics. It is used to quantify defined variables such as behaviours, attitudes, opinions, and other variables – and generalize results from a sample population. Quantitative research uses measurable data to formulate facts and uncover patterns in research through the measurement of variables and statistical analysis (Johnson & Christensen 2012:34-5; and Kaur 2016:94). The use of numerical data for the research descriptions and analysis reduces the amount of time and effort which the investigator would have invested in describing his results. Also, the use of scientific methods for data collection and analysis make generalization possible with this type of approach (Lichtman 2013:4 quoted in Alves & Coimbra 2014:1047).

Authors Creswell & Plano-Clerk (2011:57) have described the nature of quantitative research as follows:

“Quantitative research is a mode of inquiry used often for deductive research when the goal is to test theories or hypotheses, gather descriptive information, or examine relationships among variables. These variables are measured and yield numeric data that can be analyzed statistically. Quantitative data have the potential to provide measurable evidence, to help to establish (probable) cause and effect to create the possibility of replication and generalization to a population, to facilitate the comparison of groups, and to provide insight into a breadth of experiences”.

However, it is noted that quantitative methods can be limiting in exploring and explaining the reasons why a particular phenomenon occurs (Johnson & Christensen 2012:35). Researcher detachment from the respondents is also a weakness within the quantitative research approach. Researcher detachment means that the researcher is an “observer” or an “outside looking in”. With this type of researcher/respondent relationship, it’s difficult to get an in-depth study of the phenomena within its natural setting (Johnson & Christensen 2012:36).

For example, the respondents in this study reported that the WHOQOL-HIV BREF, a structured instrument with close-ended questions lacked “why” questions that would have allowed them to provide narratives to justify their scores on the Likert scale. Resultantly, the researcher used in-depth interviews in the qualitative phase to explore the themes and patterns generated by the quantitative phase hence minimizing the weaknesses of the quantitative approach.

3.2.1.2 The Nature of Qualitative Research:

Qualitative research uses a naturalistic approach that aims to understand phenomena in context-specific settings such as “real world” settings where the investigator does not try to manipulate the phenomenon of interest (Patton 2015:62). Qualitative research broadly defined, means “any kind of research that produces findings not arrived at through statistical procedures or other means of quantification” (De Vaus 2014:6). Hence, the qualitative research approach provides abundant data about real life people and situations (De Vaus 2014:6; Leedy & Ormrod, 2014:15).

The reliance on the collection of non-numerical primary data such as words and pictures by the researcher makes qualitative research well-suited for providing factual and descriptive information (Johnson & Christensen 2012: 29-37). Expressions and experiences of the respondents are easily understood even when there is little or no information about them (Leedy & Ormrod, 2014:141). As applied to this study, the qualitative research component used in-depth interviews to capture the experiences and perspectives of YALPH, hence providing insight into their HRQOL and how it could be improved. This nature of detail could not be generated by the WHOQOL-HIV BREF alone.

According to Patton (2015:63), qualitative research is a systematic and rigorous form of inquiry that uses methods of data collection such as in-depth interviews, ethnographic observation and review of documents. Qualitative information helps investigators to understand processes, especially those that emerge over time, provide detailed information about setting or context, and emphasize the perspectives of respondents through quotes. Qualitative research allows for flexibility in sampling and information gathering. Although a sample size may exist, an additional sample may be used if there is a need to further explore and build on an issue, and the researcher has been provided with informants for further exploration of that issue. In the case of this study, data collection was ended after the attainment of data saturation, which occurred before reaching the predetermined sample.

However, the critiques of qualitative research assert that the non-use of numbers by qualitative researchers makes it difficult and impossible to simplify findings and observations. Qualitative researchers believe that the social world (phenomena and experiences) has many dimensions, hence explanations are based on the interpretations of the researcher (Leedy & Ormrod 2014:141; De Vaus 2014:5-7).
In view of this, a proper explanation cannot be given because the result depends on the explanation of the researcher at that time of which a different researcher may give a different explanation. So, the research cannot be repeated by another researcher at another place and still get the same results. Resultantly, checklists of design methods and analysis have been published in an attempt to improve rigor in qualitative research (Mays & Pope 2000:111). The guidelines include triangulation of methods, triangulation of data, use of software packages to help process the analysis once coding has taken place and respondent validation (Mays et al. 2000: 111). Those guidelines were taken into account in the design and implementation of this study.
The summary of the study design is shown in Table 3.1

Table 3.1: Summary of the Study Design

APPROACH	SAMPLE	GOAL	ANALYSIS
Quantitative survey using the WHOQOL-HIV BREF instrument.	Proportionate stratified sample of YALPH (509)	Assess the HRQOL of YALPH (patterns and associations)	Descriptive and inferential statistical analyses of social – demographic and clinical characteristics of the sample. Bivariate & multivariable statistical analysis to identify the predictors of HRQOL.
Medical records review using a standardized data abstraction instrument.	All respondents in the WHOQOL-HIV BREF survey (509).	Clinical characteristics of the individuals in the Survey.	Simple frequency and Percentages.
In-depth interviews using a semi-structured instrument.	Purposive sub-sample of YALPH who participated in the WHOQOL-HIV BREF survey (45).	Collect descriptive information on factors affecting HRQOL in the sampled YALPH.	Framework Approach to qualitative data analysis.

3.3 RESEARCH METHOD

This section describes the research setting and population, the study sample and the sampling procedure adopted for both the quantitative and qualitative phases. The data collection and analysis approaches are also detailed in this section.

3.3.1 Sampling:

3.3.1.1. The Study Setting:

The study setting refers to the place where the data is collected. In this study, data was collected from patients enrolled on ART at Botswana-Baylor Children's Clinical Centre of Excellence (Botswana-Baylor), in Gaborone, Botswana (Figure 4).

The Botswana-Baylor is the largest centre for pediatric, adolescent and young adult HIV treatment and care in Botswana. The centre is a partnership between the Government of Botswana and the Baylor College of Medicine – Baylor International Pediatric AIDS Initiative (BIPAI). The centre which was launched in 2003 is located on the campus of the Princess Marina Hospital, a national referral hospital in Gaborone. Specifically, the respondents were recruited from the Pediatric Infectious

Disease Clinic (PIDC) which serves children and adolescents aged (0-18 years); the Family Model Clinic (FMC) which serves patients who are aged 19 years and over; the pharmacy where monthly ARV refills are supplied; and the monthly Young Adults Support Group (YASG) meetings. The patients enrolled on ART at Botswana-Baylor lived mainly in Gaborone and surrounding districts including South East, Kweneng, Kgatleng, and Southern districts; thus they were drawn from diverse geographical and socio-economic environments.

Figure 4: Map of Botswana showing the location of the study site
(Source:http://www.lonelyplanet.com/maps/africa/botswana/)

3.3.1.2. Study Population:

According to Tuckman (1994:75), the population (or target group) used in a study, is that group about which the researcher is interested in gaining information and drawing conclusions. Thus, an early step in sampling is to define the population from which the sample is to be drawn. The author posits that if the population is broadly defined, external validity and generalizability will be maximized although obtaining a representative sample in such a case may be difficult. On the other hand, defining the population narrowly may facilitate the selection of a suitable sample, but may restrict conclusions and generalizations to the specific population used, which may be inconsistent with the intent of the study.

The target population for this study included male and female YALPH aged 18-30 years who were enrolled on ART at Botswana-Baylor during the study period. At the

time of sampling, there were 1375 YALPH aged (18-30 years) enrolled on ART at Botswana-Baylor. The Botswana-Baylor has the largest group of perinatally HIV infected young adults in Botswana. The patients came to the Botswana-Baylor at least once every three months to access a wide range of clinical and psychosocial support services. Thus, collecting data over three months increased the chances for all qualifying YALPH enrolled on ART at Botswana-Baylor to participate in the study.

3.3.1.3 Sampling and Sampling Procedure:

According to Francis (1995:5), a sample is a small representative set of a population. The information gathered from a sample (that is measurements, facts, and/or views) will normally give a good indication of the measurements, facts, and/or views of the population from which it was drawn. According to Patton (2015:69), the sampling strategy and the sample size must be selected to fit the purpose of the study, the resources available, the questions being asked and the constraints being faced.

Regarding the sample size, it has been noted that there is no universal formula for calculating the size of a sample. The size of the sample varies with the research questions and research design (Kaur 2016:94). However, as a starting point, two facts are well known from statistical theory and should be remembered. 1) The larger the size of the sample, the more precise will be the information given about the population; and 2) above a certain size, little extra information is given by increasing the sample size (Parahoo 2014:272).

3.3.1.3.1 Sampling for the Quantitative Phase:

In sampling for the quantitative approach, a list of all young adults enrolled on ART at Botswana-Baylor was abstracted from the electronic medical records and used as the sampling frame. The representative sample size for the total population of 1375 YALPH calculated based on 99% confidence interval and 5% margin of error was 509 respondents. The sample size of 509 respondents met the WHOQOL-HIV Group's recommendation of a minimum of 300 respondents for sites where the WHOQOL-HIV BREF instrument is used for the first time (WHOQOL-Group 2003:347-57).

Proportionate stratified sampling technique was used for the quantitative phase. Proportionate stratified sampling is a sampling method in which different sub-groups in a population (strata), are identified and in which the number of elements drawn

from each stratum is proportionate to the relative number of elements in each stratum (Patton 2015:97). Proportionate stratified sampling provides greater control over the composition of the sample hence assuring the researcher of representativeness of the sample in terms of the stratification variables (Francis 1995:56). Stratification can help to ensure that not only the overall population but also that key subgroups of the population are represented.

The total population of all YALPH at Botswana-Baylor was stratified according to gender (male and female) and age groups (18-21, 22-25 and 26-30 years). After stratification of the total population, then a proportionate number of respondents were drawn from each stratum as shown in Table 3.2. Every YALPH aged 18-30 years arriving at Botswana-Baylor for services on a data collection day was invited to participate in the study until the target number of respondents for each stratum was reached.

Table 3.2: Proportionate Stratified Sample

Gender	Total Population (N=1375)	Age Group (%)	Proportionate Stratified Sample (N=509)
Female	660	18-21 (26.42%)	135
		22-25 (17.80%)	90
		26-30 (4.11%)	21
Male	715	18-21 (29.74%)	151
		22-25 (18.29%)	93
		26-30 (3.76%)	19

3.3.1.3.2 Sampling for the Qualitative Phase:

According to Patton (2015:96), the sample size in qualitative inquiry depends on what the researcher wants to know, the purpose of the research, what will have credibility, and what can be accomplished within the available time and resources. The author asserts that in-depth information from small samples can be quite sufficient in providing complete and accurate information within a particular context, as long as the respondents are “information-rich’’ that is they possess a certain degree of expertise about the domain of inquiry (Patton 2015:97).

For the in-depth interviews, purposive sampling was used to select respondents from those who participated in the WHOQOL-HIV BREF survey. Purposeful sampling involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest

(Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood 2015:2). In addition, purposeful sampling considers in addition to knowledge and experience, the importance of availability and willingness to participate and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner (Palinkas et al. 2015:534).

Two purposeful sampling strategies were used to recruit study respondents as follows:

1) **Intensity sampling:** An intensity sample consists of information-rich cases that manifest the phenomenon of interest intensely (but not extremely) (Patton 2015: 79). According to Palinkas et al. (2015:534), intensity sampling requires the researcher to do some exploratory work to determine the nature of the phenomenon under study, then sampling intense examples of the phenomenon of interest.

In this study, intensity sampling strategy was aimed to select particular cases that would glean the most information on the factors that were significantly associated with general HRQOL as identified by the quantitative phase including the highest level of education attained, employment status, self-reported illness, and VL suppression levels. Those respondents were selected with the cooperation of clinicians and program staff at Botswana-Baylor.

2) **Maximum variation sampling:** According to Palinkas et al. (2015:534), maximum variation sampling, also known as heterogeneous sampling is a purposive sampling technique used to capture a wide range of perspectives relating to the subject of the study. The authors assert that the selection of cases with maximum variation aims to document unique or diverse variations that have emerged in adapting to different conditions and or varied lived experiences (Palinkas et al. 2015:534). The basic principle behind maximum variation sampling is to gain greater insights into a phenomenon by looking at it from multiple perspectives. This can often help the investigator to identify the various facets and commonalities that are present across the sample.

In this study, maximum variation sampling strategy was used to ensure a wide variety of YALPH was included in the qualitative sample. To achieve this, the researcher used the social-demographic and clinical information generated by the quantitative phase to select cases representing variation on dimensions of interest such as age, gender, education, employment, young mothers, parenting, living arrangements, CD4 cell count, VL levels and BMI levels, disabilities and impairments.

All the YALPH identified through the two sampling approaches agreed to participate in the study. The final sample size in this study was determined by data saturation. Saturation refers to completeness or fullness necessary to ensure that everything related to the phenomenon of inquiry that can be collected and analyzed has been done so within the limits of the forms of collection and analysis chosen (Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs & Jinks 2018:1894). According to Fusch & Ness (2015:1408) and Morse (2015:587) saturation is the gold standard of the determination of purposive sample in health science research.

In order to track and monitor saturation, the researcher combined sampling, data collection and data analysis rather than treating them as separate stages in a linear process as recommended by Moule, Aveyard & Goodman (2016:221). The researcher went through three sequential analysis rounds conducted after each set of ten in-depth interviews until no new information or themes were generated. Saturation was subjectively determined by the researcher to have occurred by the completion of thirty in-depth interviews. However, 10 more interviews were conducted to further substantiate the previous interviews.

3.3.1.4 Inclusion and Exclusion Criteria for the Quantitative and Qualitative Phases:

The inclusion criterion was that respondents were: aged between 18 to 30 years; had perinatally acquired HIV infection; and gave informed verbal and written consent to participate in the study. Excluded from the study were those: aged less than 18 years or over 30 years; had gross cognitive dysfunction that rendered them incapable of completing the WHOQOL-HIV BREF instrument or participating in in-depth interviews; and those who did not consent to participate in the study.

3.3.2 Data Collection:

3.3.2.1 Data Collection Approach and Method:

This study used quantitative methods of data collection which included assessment of the HRQOL of YALPH using the WHOQOL-HIV BREF, medical records review to collect social-demographic and clinical data and qualitative data collected through in-depth interviews.

3.3.2.1.1 Assessment of HRQOL using the WHOQOL-HIV BREF Instrument:

In the case of this study, the WHOQOL – HIV BREF instrument was used to assess the respondents' HRQOL (Appendix 1). The nature of the WHOQOL-HIV BREF instrument is detailed in section 1.4.3. Before this study, the WHOQOL-HIV BREF instrument was previously used and validated in Botswana by Ndubuka et al. (2016:3).

3.3.2.1.2 Medical Records Review:

The medical record review is a type of research design in which pre-recorded, patient-centered data is used to answer research questions (Kaji, Schriger & Green 2014:46). When conducting a medical records review, a standardized abstraction form helps to ensure a measure of consistency in the abstraction while helping to reduce error in data collection (Vassar & Holzman 2013:4).

In this study, a medical records review form was developed by the researcher to abstract demographic and clinical information from patients' medical records maintained at Botswana-Baylor (Appendix 2). Clinical, laboratory and demographic variables abstracted using the form included: date of birth, the mode of HIV transmission categorized as MTCT (yes or no); ART initiation date; most recent CD4 cell count and VL levels (<400 copies per ml and >400 copies per ml); and body mass index (BMI).

3.3.2.1.3 In-Depth Interviews:

In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of interviewees in order to explore their perspectives on a particular phenomenon (Patton 2015:65). In this study, in-depth interviews were aimed mainly to provide context to the themes and trends generated by the WHOQOL-HIV BREF survey, hence offering a complete picture of factors affecting the HRQOL of YALPH.

There are two reasons why the in-depth interview method was appropriate for this study. First of all, interviews allow for the self-report of perceptions and feelings from the interviewees. Various authors including Fontana and Frey (1994:363) and Brink and Wood (1998:337) assert that when the objective is to find out what people know, feel or think, the easiest and most effective way is to ask directly of the person. Secondly and especially in the case of YALPH's interviews, since the interviewer was present with the respondent, there was an opportunity to clarify the meaning of questions if the interviewees did not understand; and also, to clarify respondents' responses.

The standardized open-ended interview approach using a set of open-ended questions was used (Patton 2015:62). Standardized questions were preferred because this study included a relatively homogenous population of YALPH, in which respondents' experiences and domains of knowledge were similar. A similar set of questions had to be asked of all respondents otherwise one could never achieve data saturation; as new responses would be given to newly introduced questions. However, probe and follow-up questions were asked as necessary (Appendix 3).

3.3.2.2 Development and Testing of Data Collection Instruments

The development and testing of tools used in this study aimed to ensure validity and reliability. According to Parahoo (2014:272) if the information gathered is to be useful to policymakers and practitioners, the instrument should produce reliable and valid data. The validity of a tool is determined by the extent to which it addresses the research questions and objectives of the study. The reliability is determined by the consistency with which respondents understand and respond to all questions (Parahoo, 2014:272).

3.3.2.2.1 WHOQOL-HIV BREF Survey Instrument:

The WHOQOL-HIV BREF was developed from the longer WHOQOL-HIV instrument by the WHO to provide a reliable and valid measure of HRQOL that is specific to PLWH (WHOQOL Group 2003:4). The WHOQOL-HIV BREF was developed in focus groups of people with HIV across 6 countries, ensuring that the items have conceptual and semantic relevance across cultures (O'Connell & Skevington 2012:5). For this study, questions were added to the instrument to collect additional social-demographic information including place of residence; living arrangements; access to information (radio, TV, newspapers, internet, phone); biological mother alive (yes or no); biological mother on ART (yes or no); and having a biological child (yes or no).

Before its use in this study, the items on the WHOQOL-HIV BREF instrument were translated into Setswana by a bilingual translator. The translation process aimed to achieve semantic, conceptual and normative equivalence rather than literal translation. The translated version of the instrument was then translated back into English by an independent translator. Discrepancies were reconciled by the two translators. Respondents had the choice to use the Setswana or English version of the tool.

The WHOQOL-HIV BREF instrument was pilot tested before its use in this study. According to Van Tielingen and Company (1995:21), pilot-tests are small-scale versions of research that are conducted to assess the study design, its feasibility, and evaluate the methodology and procedures of the investigation. Specifically, pilot studies allow researchers to assess and evaluate any potential sampling concerns or impact resulting from inclusion and exclusion criteria (Jansenet 2005:6).

The WHOQOL-HIV BREF was pilot-tested with ten conveniently selected YALPH at Botswana-Baylor using a cognitive interviewing approach. According to Latcheva (2011:9), cognitive interviewing involves the researcher asking the interviewee to share their thoughts about the questions as they go through a survey questionnaire and tell them everything they are thinking. Cognitive interviewing aims to identify non-clear or difficult questions that may result in response errors, understand how respondents interpret and understand the questions, and to identify potential problems that may arise in prospective survey questionnaires. This allows understanding of the questionnaire from the interviewee's perspective rather than that of the interviewer.

In pilot-testing the tool, the researcher read out the questions directly from the WHOQOL-HIV BREF instrument and respondents were asked if they had understood the question. The call for repetition or need for further explanation was noted as a proxy indicator of question difficulty. Once the interviewees responded, they were asked to explain their responses and where possible give examples. The pilot-testing exercise showed that the YALPH understood the items very well and were able to rate their QOL on a five-point Linkert scale without difficulty. However, one item on the WHOQOL-HIV BREF instrument (Appendix 1) was found to be sensitive: F15.3 "how satisfied are you with your sex life?" The item made some respondents uncomfortable and the question was likely to lead to errors associated with socially desirable responses since sex per se is regarded as a risk factor for HIV transmission by the local society in Botswana as shown in the quote below:

"It is not all of us who indulge in sexual intercourse. That is why I did not attempt the sexual intercourse question" Male, 19 years

In the main study, to minimize response effect, the researcher explained why that potentially sensitive question regarding satisfaction with sex life was included in this study in line with guidelines by Tourangeau (2010:5). This was both in the information sheet (Appendix 4) and the verbal explanation of the WHOQOL-HIV BREF survey by the researcher. The explanation aimed to give the respondents trust and comfort to respond to the question and be able to comfortably rank satisfaction with their sex life on the five point Linkert scale.

3.3.2.2.2 Medical Records Review Form:

The researcher developed a medical records review form to collect respondents' demographic and clinical information from medical records maintained at Botswana-Baylor. In designing the tool, the researcher ensured that the fields on the abstraction form had logical organization similar in flow to the format of the original medical records where the data was abstracted from. An electronic version of the tool in MS Access was developed and used for direct data entry to avoid errors from data transposition from paper forms. The electronic version of the tool included error messages for incomplete fields. A pilot-test of the medical records review form was conducted with 10 cases to ensure that all fields of the tool could be populated. The

results of the pilot-test showed that the tool was well aligned with the source electronic medical records.

3.3.2.2.3 In-Depth Interview Guide:

The researcher developed the in-depth interview guide with open-ended questions based on the results of the WHOQOL-HIV BREF survey, the review of literature, and through consultation with service providers at Botswana-Baylor (Appendix 3).

Since this was a sequential explanatory design study, the goal of the in-depth interviews was to explore and elaborate on the results from the quantitative phase of the study. Thus, the open-ended questions in the interview guide explored the role of the factors which demonstrated statistically significant predictive power for HRQOL in the sample of YALPH including education, employment, VL suppression and illness perception. Additional open-ended questions were included in order to explore other factors affecting HRQOL of YALPH which were identified through literature review. Although those other factors may not have shown a significant effect on the HRQOL in the quantitative survey, their role was explored through the in-depth interviews.

The interview guide was peer-reviewed by the staff at Botswana-Baylor including a paediatrician, a social worker, a peer educator, and a public health specialist. Group recommendations were incorporated into the interview guide. Some of the experts' observations informed the ordering and wording of the questions.

The interview guide was pilot-tested with 4 YALPH to evaluate the usability, appropriateness and clarity of the tool using cognitive interviewing. The progress of questions, amount of clarifications needed, the information collected from each question and time needed to complete the interviews were evaluated. Potentially unclear questions in the tool were identified and modified accordingly. The instrument was revised as necessary until the interviews lasted no more than 45-60 minutes.

All YALPH who participated in the development and pilot-testing of data collection instruments were excluded from the main study as their exposure to the instruments was likely to have changed their perspectives about their HRQOL.

3.3.2.3 Characteristics of the Data Collection Instruments:

3.3.2.3.1 WHOQOL-HIV BREF Instrument:

The WHOQOL-HIV BREF is a structured, 31-item instrument that is either self-administered or interviewer assisted (O'Connell & Skevington 2012: 452- 60). The tool asks the interviewee to rate his or her QOL in many ways, during the last two weeks preceding the interview. All questions of the WHOQOL-HIV BREF instrument are closed. The tool also contains questions to collect clinical and demographic information about the respondent. The instrument is brief and takes anywhere from 15-30 minutes to complete.

The tool covers the respondent's perception of the overall QOL within the 6 (six) broad domains: Physical, Psychological, Level of Independence, Social, Environmental and Spiritual. There is also a general facet that measures general health perceptions and the overall QOL.

The Physical domain contains 4 facets including pain and discomfort, energy and fatigue, sleep and rest, and symptoms related to HIV.

The Psychological domain contains 5 facets including positive feelings, concentration, self-esteem, body image and appearance, and negative feelings.

The Level of Independence domain contains 4 facets: mobility, activities of daily living, dependence on medication and treatment, and work capacity.

The Social Relationships domain contains 4 facets including personal relationships, social support, sexual activity, social inclusion.

The Environment domain contains 8 facets including physical safety and security, home environment, financial resources, health, and social care: accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation/ leisure activities, physical environment, transport.

The Spirituality, religion and personal beliefs domain contain 4 facets including: personal beliefs, forgiveness and blame, concerns about the future, death and dying.

Items are rated on a 5-point Likert interval scale where 1 indicates low, negative perceptions, and 5 indicates high, positive perceptions. Facet scores are the mean of the four items in each facet. Domain scores are obtained by adding the facet means

in the respective domain, dividing by the number of facets in that domain, and multiplying by 4, with scores ranging from 4 (worst possible QOL) to 20 (best possible QOL).

3.3.2.3.2 Medical Records Review Form:

Vassar & Holzmann (2013:2-5) stress the need for quality control measures and minimization of abstractor error in collecting information from medical records. In designing the medical records review form, the researcher aimed to minimize errors by ensuring that the form listed the items in the order they appeared in the Electronic Medical Records at Botswana-Baylor. The electronic version of the form showed error messages for incomplete fields which helped to reduce missing data rates. Each case had a study identification number that linked with the associated WHOQOL-HIV BREF data.

3.3.2.3.3 In-depth interview guide:

The in-depth interview guide comprised of a set of open-ended questions. This was in line with the mixed methods explanatory design of the study which required in-depth interviews to provide a deeper understanding and explorations of the factors affecting the HRQOL of YALPH which were identified by the quantitative phase.

The in-depth interview guide was designed to achieve standardization by obtaining information in a consistent way for all respondents in the qualitative phase. In that respect, the researcher had to ensure that a similar set of questions was asked of all respondents otherwise the study would fail to achieve saturation as new responses would be given to newly introduced questions. This meant that a particular set of questions had to be asked as a foundation and then appropriate follow-up questions were made in line with individual responses. In addition, the tool allowed flexibility in that some questions were included as the researcher learned more about the YALPH experiences in line with the evolutionary characteristic of in-depth interviews (Patton 2015:59).

3.3.2.4. Data Collection Process:

3.3.2.4.1 Quantitative Phase (WHOQOL-HIV BREF Survey):

The data for this study was collected by the researcher and a trained research assistant. Every young adult coming to Botswana-Baylor for services on a data collection day was systematically approached privately on arrival, without disturbing the routines of the busy clinic. The majority of the respondents were identified and invited to participate in the study as they waited for clinical reviews and ART refill or at the Young Adult Support Group meeting. If the YALPH agreed to participate, the study was explained to them and a written study information sheet handed to them after which they were required to sign the study consent form (Appendix 4).

Noting that increased chance of non-response could have introduced bias and errors into the study, the researcher implemented various procedures to encourage as many selected respondents as possible to participate without coercing them. One concrete approach was to inform them of the purpose of the study, explaining that their participation was essential for the study's success since they belong to a limited number of YALPH enrolled on ART at Botswana-Baylor.

Respondents were given the WHOQOL-HIV BREF instrument to complete themselves after the researcher or the research assistant went through it with them. For respondents who could not complete the WHOQOL-HIV BREF instrument independently, interviewer assistance was provided. In such cases, the researcher read the items to the respondent and recorded their responses on the instrument. The respondents completed the surveys at the clinic while waiting for other services. However, in all cases, the researcher was always available to provide information where clarity was needed by the respondent. This helped to reduce missing data and increase the item response rates. On average the time taken to complete the WHOQOL-HIV BREF instrument was between 15 - 25 minutes.

3.3.2.4.2 Medical Records Review:

The most recent (<6 months) laboratory and clinical assessment of CD4, VL, and BMI was abstracted from the electronic medical records at Botswana-Baylor immediately after the respondents completed the WHOQOL-HIV BREF instrument. The medical records information was also used to verify social-demographic and other relevant information which the respondent had provided as part of the survey or in-depth interviews.

3.3.2.4.3 In-depth Interviews:

The researcher contacted the sampled respondents by phone to arrange for the in-depth interviews which in most cases coincided with a routine appointment at Botswana-Baylor Clinic. After respondents agreed to participate and came to Botswana-Baylor, the researcher obtained written informed consent to participate in the interview. The written informed consent simultaneously granted permission to audio-record the interviews without collecting personal information that could identify a respondent. All interviews were conducted in a private room at the Botswana-Baylor clinic which provided privacy and comfort to the respondent.

The in-depth interviews were conducted by the researcher and a trained research assistant which enabled uniformity of approach since only two interviewers were involved. The interviewers could sense if a question had not been fully understood and could follow-up on the spot and provide standardized explanations and descriptions of concepts. Follow-up questions were added based on the individual respondents' responses. In all cases, the in-depth interviews were audiotaped and subsequently transcribed verbatim. The interviews lasted from 30-45 minutes.

Shortly after each in-depth interview, the researcher wrote extensive field notes to maintain an audit trail as described by Lavelle, Vuk and Barber (2013:272). The field notes allowed the researcher to reflect on the interview and to decrease pre-conceived perceptions in an attempt to gain a less biased interpretation of the data.

The interviews with YALPH required patience, adaptability, empathy and unconditional acceptance. Overall, respondents had a lot to share, which was related to living with perinatally acquired HIV. The researcher to the extent possible avoided the sessions turning into counselling sessions. However, the researcher made time to

listen, provide information or refer the respondent to relevant Botswana-Baylor staff for clinical, psychological or other support.

The respondents reciprocated by sharing their experiences, views and perspectives openly. Although there was no secondary therapeutic agenda in the study, talking about the subject openly may however have led the respondents to review their beliefs, attitudes and convictions about their lives and wellbeing; and respondents could have benefited from the catharsis involved in sharing their experiences and ventilating their views and feelings.

3.3.2.5 Study Ethical Considerations:

According to the Declaration of Helsinki on ethical principles for medical research involving human subjects (World Medical Association, 1964 and amended 2008:1-5), considerations related to the well-being of the human subject should take precedence over the interests of science and society. The declaration posits that a researcher must promote and safeguard the life, health, privacy and dignity of the human subject. This implies that people who are asked to participate in research studies have the right to protection.

Since this study used a mixed methods design combining quantitative and qualitative research methods, considerations were made to address typical ethical issues that arise in both forms of inquiry. The following ethical considerations were made:

3.3.2.5.1 Permission to Conduct the Research:

Administrative and Ethical approval was taken from the Institutional Review Board of Botswana-Baylor (BBCCOE/14). The study was approved by Botswana's Ministry of Health and Welfare's Health Research Development Committee (HRDC) with permit number (PPME-13/18/1 Vol VII (318). The Higher Degrees Committee of the Department of Health Studies, University of South Africa, granted ethical approval for the study to be conducted with reference number HSHDC/7/012.

3.3.2.5.2 Voluntary Participation (Autonomy):

To ensure autonomy in this study, the researcher provided detailed information about the study from a written introductory statement including what the research was about and how the information would be used and also reassured potential research respondents that they had the right to withdraw at any time from the survey or the

interview process. In addition, a study information sheet was handed to the potential respondent. The subject's right to refuse to participate and how this wouldn't disadvantage them was emphasized.

3.3.2.5.3 Informed Consent:

When equipped with sufficient information, potential respondents should be requested to provide signed consent for participation in a research study. Johnson & Christensen (2012:422) define informed consent as "agreeing to participate in a study after being informed of its purpose, procedure, risks, benefit, alternative procedures and limits of confidentiality". According to Parahoo (2014:258), informed consent is also grounded on the ethical principle of autonomy in that "it encompasses the notion of being a self-governing person with decision-making capacity".

When obtaining informed consent in this study, the researcher was particularly cautious of the fact that the potential respondents had a dependent relationship with the Botswana-Baylor Clinic and wanted to avoid consent under duress. In that case, the informed consent was obtained after an elaborate explanation of the potential respondents' right to opt-out of the study. Respondents were informed that participating in the study was voluntary and that refusal to participate would not compromise the medical care and other services they received from the clinic. The right to withdraw from the study at any time was also assured.

Written and signed informed consent was obtained from each respondent who completed the WHOQOL - HIV BREF instrument. Basic consent to participate in the study included permission to link WHOQOL - HIV BREF data with patients' routine clinical data records. Respondents were told that this was an optional consent and that they could refuse the researchers to use their medical information and still participate in the WHOHRQOL-HIV BREF survey or in-depth interviews part of the study. Respondents were informed that the abstracted medical data would not be linked back to any identifying information in the medical records.

Consent was also sought from those who participated in the in-depth interviews. All the respondents in the in-depth interviews were informed and consented to be audio recorded before the interview began.

3.3.2.5.4 Confidentiality:

Similar to the concerns over privacy and anonymity is the concern over confidentiality, that is, who will have access to the data? In research, respondents may be concerned that others could gain access to research data and use them to make judgment of character. Research respondents, therefore, have the right to expect that data collected from them to be treated with confidentiality. In this study, each respondent was informed of their right to privacy and the right not to provide selective information to the researcher.

In the case of the WHOQOL-HIV BREF survey, respondents were identified only by a unique study code number and were instructed not to write their name or patient number on the instrument to maintain their anonymity. The rooms at Botswana-Baylor Clinic where the instruments were completed and interviews were conducted provided for confidentiality and privacy. Completed instruments were handed directly to the researchers to ensure that their answers were kept confidential.

The researcher collected respondents' contacts so that they could be contacted for the in-depth interview phase or for member checking of the results. Respondent code numbers and contacts were entered into a study log which was stored separately from the completed instruments in secure storage.

For in-depth interviews, since the description of lived experiences tended to be very personal in nature, to facilitate greater disclosure and self-expression, the researcher assured respondents of strict adherence to data protection and respondents' confidentiality; and sought specific permissions from respondents to quote from what the respondents said in writing-up the research report without using their names.

The respondents were also informed about the system by which the study data would be kept confidential. Assurance was given to the respondents about the anonymity of the data, with the removal of names and any other identifying information from the instruments, field notes and published information. In-depth interview transcripts were sanitized by removing any comments or information that may have compromised confidentiality. In writing the report, all respondents identifying information was left out of the quotes to maintain confidentiality.

All completed questionnaires were securely locked up. All information was entered into a password-protected computer to which only the researcher and the research assistant had access. The completed questionnaires and the computer records will

be discarded in line with Botswana-Baylor data management, storage and disposal protocols.

3.3.2.5.4 Minimising Possible Impact of the Research on Respondents:

All efforts were made to ensure that the research itself was not unreasonably distressing to respondents. A social worker and peer educator at Botswana-Baylor helped to review the study protocol to assess the potential contribution of the study to society and the potential effect on the respondents. Questions in the data collection tools were evaluated for sources of distress to YALPH. The recommendations of the reviewers were integrated into the design of the data collection approaches and tools.

Several strategies were put in place in case the involvement in the study re-awoke sad memories or uncomfortable feelings as a result of completing the questionnaire or discussing painful or difficult experiences living with perinatally acquired HIV during in-depth interviews. The researcher who conducted interviews was a mature person with counselling and research experience and a sensitive manner. As with any research interview, the researcher would pause if the respondent became emotional and perhaps suspend the interview for a time, only resuming when the interviewee was calmer and able to decide to do so.

Interview closures were carefully handled. The researcher would remain available to the respondent for a time after the completion of the interview in case the respondent wanted to ask questions or discuss any issues. Respondents who needed additional help were referred to the relevant professionals at Botswana-Baylor.

3.4 DATA PROCESSING AND ANALYSIS

3.4.1 Quantitative Data Analysis:

The data which was collected through the WHOQOL-HIV BREF survey and the review of the medical records was verified for completeness and consistency immediately after it was collected and during the overall data cleaning exercise.

For WHOQOL-HIV BREF, the scores for the six domains and general QOL were calculated according to the manual for checking, scoring and coding WHOQOL-HIV BREF (WHOQOL Group 2002:51-54). The domain scores range between 4 and 20, with 4 signifying the worst result and 20 signifying the best result. General QOL score

ranges between 1 and 5, with 1 corresponding to very poor QOL and 5 corresponding to very good QOL. This was followed by internal consistency assessment using Cronbach's Alpha coefficient to assess the reliability of the instrument.

Descriptive analysis was performed by reporting the means and standard deviations of all continuous variables whilst percentages/proportions were used for categorical variables. Bivariate analyses were performed using both the t and chi-square tests to determine the associations between factors of interest and the general QOL. The variables which were associated with the general QOL at less than 10% level of significance were included into the multivariable analysis – performed using the logistic regression approach.

The general QOL was the outcome of interest and was categorized into a binary variable using 3.0 as the cut-off. A general QOL score less than or equal to 3.0 was considered poor whilst a score greater than 3.0 represented good general QOL. The goodness of fit for the final-general QOL model was evaluated using the ROC curve to determine its predictive ability. For triangulation purposes, adjusted factors were also assessed independently against six domains of QOL using the ANOVA and t-tests. All these analyses were performed using the SPSS Inc. software version 16.0 (statistical package for social science, SPSS Inc., Chicago, IL, USA).

3.4.2 Qualitative Data Analysis:

Creswell (2009:183) describes qualitative data analysis as "a process that involves making sense out of text and image data and further involves preparing the data for analysis; conducting different analyses; moving deeper into understanding the data; representing the data and making interpretation of the larger meaning of data".

In analyzing the qualitative data, the general procedures of the Framework Approach to qualitative data analysis as described by Richie & Lewis (2003:15) quoted in (Hackett & Strickland 2018:3) was followed. The Framework Approach provided a step-by-step guide to the management and thematic analysis of data, which was particularly helpful as its systematic nature helped to effectively organize and reduce data (Gale, Heath, Cameron, Rashid & Redwood 2013:4-5) quoted in (Trankle, Usherwood, Abbott, Roberts, Crampton, Girgis, Riskallah, Chang, Saini & Reath 2019:4). The Framework Approach was selected because of its proven suitability to the analysis of cross-sectional descriptive data enabling different aspects of the

phenomena under investigation to be captured (Hackett & Strickland 2018:3). In addition, the in-depth interviews in this study generated extensive open-form responses and large amounts of data which called for the application of the Framework Approach to organise, process and analyse.

The Framework Approach to data analysis follows a common set of principles including: transcribing the interviews; immersing oneself within the data to gain detailed insights of the phenomena being explored; developing a data coding system; and linking codes or units of data to form overarching categories and themes (Hackett & Strickland 2018:3; and Parkinson, Eatough, Holmes, Stapley, Target & Midgley 2016:120).

Following the principles of the Framework Approach, the transcripts from the first 5 in-depth interviews were read multiple times by the researcher in order to gain detailed insights into the descriptions provided by the respondents. The process initially involved using printed versions of the transcripts with key phrases, sentences and paragraphs highlighted and comments written in the margins to record what the respondents were describing regarding their life experiences as YALPH. Key phrases, sentences and paragraphs were summarized using respondents' words. Then the researcher identified the issues that were occurring most frequently across transcripts. Codes were developed from these respondents' words and descriptions from which a coding matrix in excel spreadsheet was developed. Codes were then grouped into categories to develop subthemes. Appropriate quotations selected from the transcripts were used to support the identified themes.

The codes and categories were refined over the consequent 5 interviews. The final categories included those which emerged inductively from the in-depth interview data as well as categories derived deductively from the results of the quantitative phase and the literature review. The codes, the categories and the transcripts from which they were derived were reviewed by two experienced researchers (a psychologist and a public health specialist) to ensure rigour of the study. The subthemes were then linked to the components of the Ferrans Conceptual Model of HRQOL which formed the overarching themes.

The data generated from in-depth interviews showed that the sample of YALPH was quite homogenous and there were very close similarities in their experiences and world views hence making it easy to code and categorize the data (Appendix 5). In

addition, since this phase of the study was explanatory, extensive quotations to be used in reporting the results were identified to keep the issues expressed by the respondents more succinct than abstract.

3.5.0 RIGOUR IN QUALITATIVE AND QUANTITATIVE PHASES:

Creswell & Plano-Clerk (2011:57) advocate that mixed methods investigations should demonstrate rigor using the same criteria as would be used in a quantitative and qualitative investigation, as well as specific mixed methods criteria. In this section, the strategies adopted by the researcher to enhance rigor in this study are outlined.

3.5.1 Validity:

According to Parahoo (2014:294), the study findings must be credible in the final analysis; and for credibility to occur the data collected should be rigorously checked for accuracy until there is sufficient evidence of indisputable information. Validity is about the correctness and truthfulness of the inferences that are made from the study (Johnson & Christensen 2012:245). In addition, Joppe (2000:599) asserts that validity determines whether the research truly measures that which it was meant to measure or how truthful the research results are. Validity is broadly measured in two dimensions, of internal and external validity.

3.5.1.1 Internal Validity:

Internal validity is the extent to which the study accurately measures or assesses the specific concept that the researcher is attempting to measure. According to Tuckman (1994:46), a study has internal validity if the outcome of the study is a function of the phenomenon being tested or studied rather than the result of other causes not systematically dealt with in the study. According to Johnson & Christensen (2012:247), “internal validity is simply referred to as causal validity because it is about establishing trustworthy evidence about cause and effect”. Internal validity is about exploring the cause and effect relationship of a phenomenon under study. This applies to quantitative research. It is concerned with whether the study has taken into consideration all other factors, which may affect the changes that have been noted in a population or individuals. According to Johnson and Christensen (2012:268),

quantitative researchers are more concerned about cause and effects than qualitative researchers are.

Within the HRQOL field, certain measurements are utilized to determine the validity and reliability of the tools in question. The methods used to measure validity and reliability within the HRQOL research includes the use of Cronbach's Alpha coefficient. According to Tavakol & Dennick (2011:53), Cronbach's Alpha coefficient is a measure that is used to calculate the internal consistency of a data collection tool. The authors assert that the goal of HRQOL tools is to demonstrate high internal consistency, with higher consistency having a Cronbach's Alpha coefficient closer to 1, and that it is generally accepted that values greater than 0.7 indicate good reliability and thus validity (O'Connell & Skevington 2012:458). In this study, the Cronbach's Alpha coefficient calculated to determine the internal consistency reliability of different HRQOL dimensions ranged from 0.83 to 0.91.

Johnson & Christensen (2012:256) define external validity as "the extent to which the study results can be generalized to and across populations of persons, settings, times, outcomes and treatment variations**".** In quantitative research, generalisability is viewed as "the extent to which it is possible to generalize from the data and context of the research study to broader populations and settings" (Van de Riet & Durreheim 2008:91). Generalisability in this study was seen as very important given the growing numbers of YALPH in Botswana and the paucity of information on how their HRQOL could be promoted. In the case of this study, external validity refers to the extent to which the results can be generalised to or representative of the population of YALPH at Botswana-Baylor and across Botswana.

According to Bless, Higson-Smith and Kagee (2006:45), external validity assumes that a study's findings represent a sample and that if the sample has been properly selected, the findings can then be generalized to the total population from which the sample was drawn. In order to achieve high external validity, the sample must be large enough to be representative of the total population, and the study must be as close as possible to the situational reality of that community or population. For the quantitative phase of this study, stratified proportionate sampling method was used and respondent enrolment continued until the sample size ensured adequate representation of the population of YALPH at Botswana-Baylor.

For the in-depth interviews, the sample size was sufficient as it led to data saturation, thus increasing external validity. Although qualitative sampling strategies do not aim to identify a statistically representative set of respondents, for this study, data from in-depth interviews was collected until saturation was reached implying that all themes and subthemes on HRQOL from this population were fully fleshed out.

3.5.2 Reliability:

Reliability is the consistency or stability of the test score or measurement tool. Johnson & Christensen (2012:46) further claim that if an assessment produces reliable scores, the scores will be similar on every occasion. Parahoo (2014:279) also adds that "reliability in quantitative terms is the consistency with which the data collection tool measures what it is supposed to measure." A reliable tool should be able to produce the same results if used in a different setup or group on every occasion that it is used. The reliability of the WHOQOL-HIV BREF has been established by several studies internationally. In addition, reliability can be improved by pretesting the research tool or instrument through piloting the questions, or through the use of questions that have been used previously in other rigorous professionally conducted studies (Parahoo 2014:280). For this study, the researcher enhanced reliability by pretesting all the data collection tools. The pilot testing was done on a small group similar in characteristics to the intended respondents.

3.5.3 Trustworthiness:

Lincoln and Guba (1985:300) describe trustworthiness as the value, applicability, neutrality and consistency of an inquiry. The trustworthiness of a research study is important to evaluate its worth. Trustworthiness is achieved through strategies that demonstrate credibility, transferability, dependability and conformability (Lincoln& Guba 1995:300).

3.5.3.1 Credibility:

This study improved credibility (confidence in the truth of the findings) through the use of mixed methods of data collection, that is, methods triangulation. Triangulation is described by Noble & Smith (2015:204) as "using multiple investigators, multiple sources of data, or multiple methods to confirm the emerging findings". Multiple methods triangulation involves using more than one method of data collection which

in this study included quantitative (WHOQOL-HIV BREF survey and medical record review) and qualitative methods (in-depth interviews).

Credibility was also enhanced by the fact that study data was collected from the same site that is at Botswana-Baylor and mainly by the researcher: making it possible to authenticate the data.

Participant validation or member checking was done with a group of 15 YALPH who had participated in the study. Member checking or respondent validation is a method for evaluating the credibility of the results. The application of member checking involves testing the data, analytic categories, interpretations and conclusions with representatives of the group from whom the data were originally obtained (Birt, Scott, Cavers, Campbell & Walter 2016:1804; and Thomas 2017:24). In this study, participant validation aimed to cross-check and to ensure that the results were congruent with the personal experiences and understanding of YALPH and to allow them to correct errors and challenge what they perceived as wrong interpretations of their perspectives. All the YALPH who participated in the validation exercise agreed with the findings of the study.

3.5.3.2 Transferability:

Transferability is the extent to which findings of a study have applicability in other contexts. Transferability of findings is defined by Birt et al. (2016:1804) as the degree to which the results of the research can apply or transfer beyond the bounds of a project. Transferability implies that the results of the research study can apply to similar situations or individuals. Transferability to other settings depends on the congruence between the context in which the research was conducted and the context to which the research findings are to be applied (Ritchie & Lewis 2003:267) quoted in (Hackett & Strickland 2018:3). Therefore, transferability requires the researcher to provide “thick descriptions” of the context and phenomena to enable others to assess the findings’ transferability. Thick description is described by Graneheim, Lindgren & Lundman (2017:29) as a way of achieving a type of external validity. By describing a phenomenon in sufficient detail, one can begin to evaluate the extent to which the conclusions drawn are transferable to other settings, situations and people.

In the case of this study, the procedural details surrounding the study population, setting, sampling, respondent selection, data collection and data analysis is well described in the study introduction and methodology chapters to appraise the readers of the authenticity of the findings and help them to make an informed judgment about whether they can transfer the findings to their situation.

3.5.3.3 Confirmability:

Confirmability is a term used to describe the level or the extent to which the findings of a study are influenced by the research respondents and not researcher bias, motivation or interest (Lincoln & Guba 1985:300). Confirmability in this study was established through an audit trail by recording and providing a detailed report of all steps taken in conducting this study from the design of the study to the collection of data and the reporting of results. For the in-depth interviews, the researcher prepared extensive field notes to keep an audit trail (Levelle et al. 2013:272). The field notes allowed the researcher to reflect on the interviews and to decrease pre-conceived perceptions in an attempt to gain a less biased interpretation of the information generated by the study. Concerning data collection and analysis, the researcher provided a detailed report of the steps taken for both quantitative and qualitative data. Additionally, methods triangulation (qualitative and quantitative), helped in corroborating and checking out the consistency of findings generated by the different data collection methods.

3.5.3.4 Dependability:

Dependability is described by Sandelowski (2000:300) as a criterion used to judge the accuracy, completeness and accessibility of the research process. The Botswana-Baylor research IRB team reviewed all the components of the study including the study proposal, data collection tools, data storage, and the study findings and report.

3.6 CONCLUSION

This chapter described the study design and methods used to achieve the study purpose and respond to the research questions put forward. The study used mixed methods of data collection and analysis. Quantitative data was gathered through a WHOQOL-HIV BREF instrument with YALPH who were enrolled on ART at Botswana-Baylor. Qualitative data was generated through in-depth interviews with a subsample of those who had participated in the quantitative phase. This provided first-hand insight into the HRQOL of YALPH.

Purposive sampling of respondents for the qualitative phase and proportionate sample for the quantitative phase were applied to target respondents with specific characteristics required for achieving the study objectives and to ensure comparison of findings for greater validity. The chapter further discussed the data collection process; the critical ethical issues observed in data collection and its analysis. A discussion also centered on how the study will guarantee reliability and validity considering the challenges of mixed methods study design.

CHAPTER FOUR

PRESENTATION OF THE RESEARCH FINDINGS

4.0 INTRODUCTION

In this chapter, the findings of the study are presented. First, the quantitative findings followed by qualitative findings.

4.1 QUANTITATIVE FINDINGS

This section presents the quantitative findings of the study generated from the WHOQOL-HIV BREF survey and retrospective medical records reviews. The quantitative results include the social-demographic and clinical characteristics of the sample, mean scores of HRQOL in various domains and the output of the bivariate and multivariate analyses.

4.1.1 Response rate:

Overall, 539 eligible YALPH were invited to participate in the study. Of these, 13 people declined to participate. The most commonly given reason for refusal to participate in the study was the inability to commit the necessary amount of time (n=9) and the rest were disinterested in the study (n=4). In total, 526 people agreed to participate and link their questionnaire responses with their medical records. However, 17 respondents were excluded from the analysis because of incomplete forms, that is, (20%) of the thirty-one items on the WHOQOL-HIV BREF instrument were not responded to. The final sample size was 509 respondents constituting a response rate of 94.43%.

4.1.2 Data Analysis:

Descriptive analysis was performed by reporting the means and standard deviations of all continuous variables whilst percentages/proportions were used for categorical variables. Bivariate analyses were performed using both the *t* and chi-square tests to determine the associations between factors of interest and the general QOL. The variables which were associated with the general QOL at the p-values < 10%, were included in the multivariable analysis – performed using the logistic regression approach. QOL was the outcome of interest in the analyses. The general QOL and six domains were entered separately as binary variables (obtained using the medians as cut-off points). The goodness of fit for the final general QOL model was evaluated using the ROC curve to determine its predictive ability. All the analyses were performed using the SPSS Inc. software version 16.0 (statistical package for social science, SPSS Inc, Chicago, IL, USA).

4.1.3 Social-Demographic Characteristics of the Sample:

The study population consisted of 509 YALPH including 255 (50.1%) females and 254 (49.9%) males. The mean age of the population was 21.7 (± 2.6) years (range 18-29.8 years). Most of the respondents (62.1%) had their biological mothers alive. The majority of respondents were single (98.82%) whereas 14% were parents (range 1-3 children). The social-demographic characteristics of the sample are presented in Table 4.1

Table 4.1: Socio-Demographic Characteristics of the Sample (n=509)

Gender, n (%)	
Male	254 (49.9)
Female	255(50.1)
Age in years Mean (± SD)	21.7 (± 2.6)
Highest level of education, n (%)	
Primary	2 (0.4)
Secondary	361 (70.9)
Tertiary/post-secondary	146 (28.7)
Marital Status, n (%)	
Living as married	6 (1.2)
Single	503 (98.8)
Living Arrangements, n (%)	
Family	462 (90.8)
Rented	43 (8.4)
Boarding School/ institutional care	4 (0.8)
Employment Status, n (%)	
In school	157 (30.8)
Unemployed	241 (47.3)
Employed	111 (21.8)
Parenting, n (%)	
Female	63 (12.4%)
Male	8 (1.6%)

Regarding their living arrangements, the majority of respondents (90.77%) resided with their families, a few (8.45%) were renting and very few (0.79%) lived in institutional care or school dormitories. Geographically, the respondents resided in Gaborone (39%), Kweneng East (34%), South East (12.4 %), Kgatleng (7.01%), southern (5.6%) and other districts (1.9%).

The highest level of education attained included: primary school (0.4%), secondary (70.9%), and tertiary (28.7%). Some respondents were students at the time of the study (30.84%). Almost half of the respondents (47.35%) were unemployed. Of the unemployed, 15% had tertiary level qualifications. Regarding information and communication, respondents had access to mobile phones (81.5%), television (72.9%), radio (62.6%), newspapers (45%) and the internet (49.3%).

4.1.4 Clinical Characteristics of the Sample:

All the clinical and laboratory data for the 509 respondents was abstracted from the electronic medical records kept at Botswana-Baylor. Detailed information on the clinical characteristics is presented in Table 4.2.

Table 4.2: Clinical Characteristics of the Sample

BMI Categories (kg/m^2), n (%)	
< 18.5	196 (38.5)
18.5 – 24.9	273 (53.6)
25.0 – 29.9	35 (6.9)
≥ 30	2 (0.4)
Missing	3 (0.6)
CD4 Counts (cells/mm^3)	
Mean (± SD)	595 (356.5)
Viral Load (cell/mL), n (%)	
< 400	441 (86.6)
> 400	68 (13.4)
Duration on ART treatment (in years)	
Mean (± SD)	12.4 (4.0)
Feeling ill (self-reported), n (%)	
No	418 (82.1)
Yes	91 (17.9)
Self-reported health status, n (%)	
Very poor	2 (0.4)
Poor	9 (1.8)
Neither poor nor good	58 (11.4)
Good	240 (47.2)
Very good	200 (39.3)
WHO Clinical Staging	
Stage I	90 (17.6)
Stage II	73 (14.3)
Stage III	191 (37.5)
Stage IV	155 (30.6)

As shown in Table 4.2, all the 509 respondents were on ART (mean duration = 12.4 years). Overall, 86.6% of the study population had suppressed VL (<400 copies per mL). The drug regimens taken by the respondents are shown in Table 4.3. The majority of respondents (87.6%) were taking once-daily drug regimens. However, the majority of the respondents who had unsuppressed VL (96%) were taking once-daily drug regimens.

Table 4.3 Respondents' ART Regimens

REGIMEN			FREQUENCY	UNSUPPRESSED VL >400 copies per mL
ABC	3TC	ATZ/r	1	
ABC	3TC	LPV/r	2	
ABC	3TC	EFV	6	
ABC	3TC	NVP	1	
AZT	3TC	LPV/r	15	1
AZT	3TC	NVP	16	1
D4T	3TC	NVP	1	
TDF	FTC	ATZ/r	1	
*TDF	FTC	DTG	307	59
*TDF	FTC	EFV	139	6
*TDF	FTC	RAL	1	
TDF	FTC	LPV/r	12	
TDF	FTC	NVP	7	1
Total			509	68

*Once-daily drug regimens

Drug name abbreviations: **ABC**- Abacavir; **AZT**- Zidovudine; **D4T**- Stavudine; **TDF**- Tenofovir ; **3TC**- Lamivudine; **FTC-** Emtricitabine; **ATZ/r**- Atazanavir (boosted with ritonavir); **EFV-**Efavirenz; **LPV/r-** Lopinavir(boosted with ritonavir); **NVP**- Nevirapine; **DTG**- Dolutegravir; **RAL**- Raltegravir

Regarding their immunological status, the mean CD4 cell count was 596 cells per mm^3; 62% had a CD4 of >500 cells per mm^3; 6.1% had a CD4 of <200 cells per mm^3 and 2.6% had a CD4 of <100 cells per mm^3.

On self-evaluation of health status, respondents rated their health as very poor (0.4%), poor (1.8%), neither poor nor good (11.4%), good (47.2%), and very good (39.3%). Only a few (17.9%) reported having some illness at the time of data collection.

To calculate Body Mass Index (BMI), the standard WHO classifications and cut-offs were used: <18.5 kg/m^2 is underweight, 18.5-24.9 kg/m^2 is normal weight, 25.0 – 29.9 is overweight and greater than or equal to 30 kg/m^2 is considered obese. Altogether, 53.6% of respondents had normal weight, whereas 38.5% were underweight, 6.9% overweight and 0.6% were obese. The mean BMI score was 19.8 kg/m^2. More males were underweight (46.85%; 119/254) compared to females (30.20%; 77/255). When BMI was categorized further into constituent parts (Table 4.4), the majority of respondents (64.2%) had BMI ranging between mild thinness (17.00 -18.49kg/m^2) and the lower range of normal weight (BMI 18.50 - 22.9kg/m^2).

Table 4.4 Detailed BMI Chart

BMI < 18.50	Underweight	Frequency
BMI <16.00 BMI 16.00-16.99 BMI 17.00-18.49	Severe Thinness Moderate Thinness Mild Thinness	38 41 117
BMI 18.50-24.99	**Normal Weight**	
BMI 18.50-22.99 BMI 23.00-24.99	Lower Range Upper Range	210 63
BMI 25.00-29.99	**Overweight/ Pre-Obese**	
BMI 25.00-27.49 BMI 27.50-29.99	Lower Range Upper Range	27 8
BMI ≥ 30	**Obese**	
BMI 30.00-34.99 BMI 35.00-39.99 BMI ≥ 40.00	Obese Class I Obese Class II Obese Class III	2 0 0
	Missing	3

Source: htt://apps.who.int/bmi/index

4.1.5 Assessment of Health-Related Quality of Life:

A total of 509 respondents completed the WHOQOL-HIV BREF instrument. The Cronbach's Alpha Coefficient calculated to determine the internal consistency reliability of different HRQOL dimensions ranged from 0.83 to 0.91. The HRQOL scores of the respondents in terms of the 31 items on the WHOQOL-HIV BREF are presented in Figure 5. The lowest weighted item scores were on items in the Environmental domain (financial resources (33.03), opportunities for leisure and recreation (52.14); Level of Independence domain (dependence on medications and treatment (53.5); and Social Relationships domain (satisfaction with sex life (56.85).

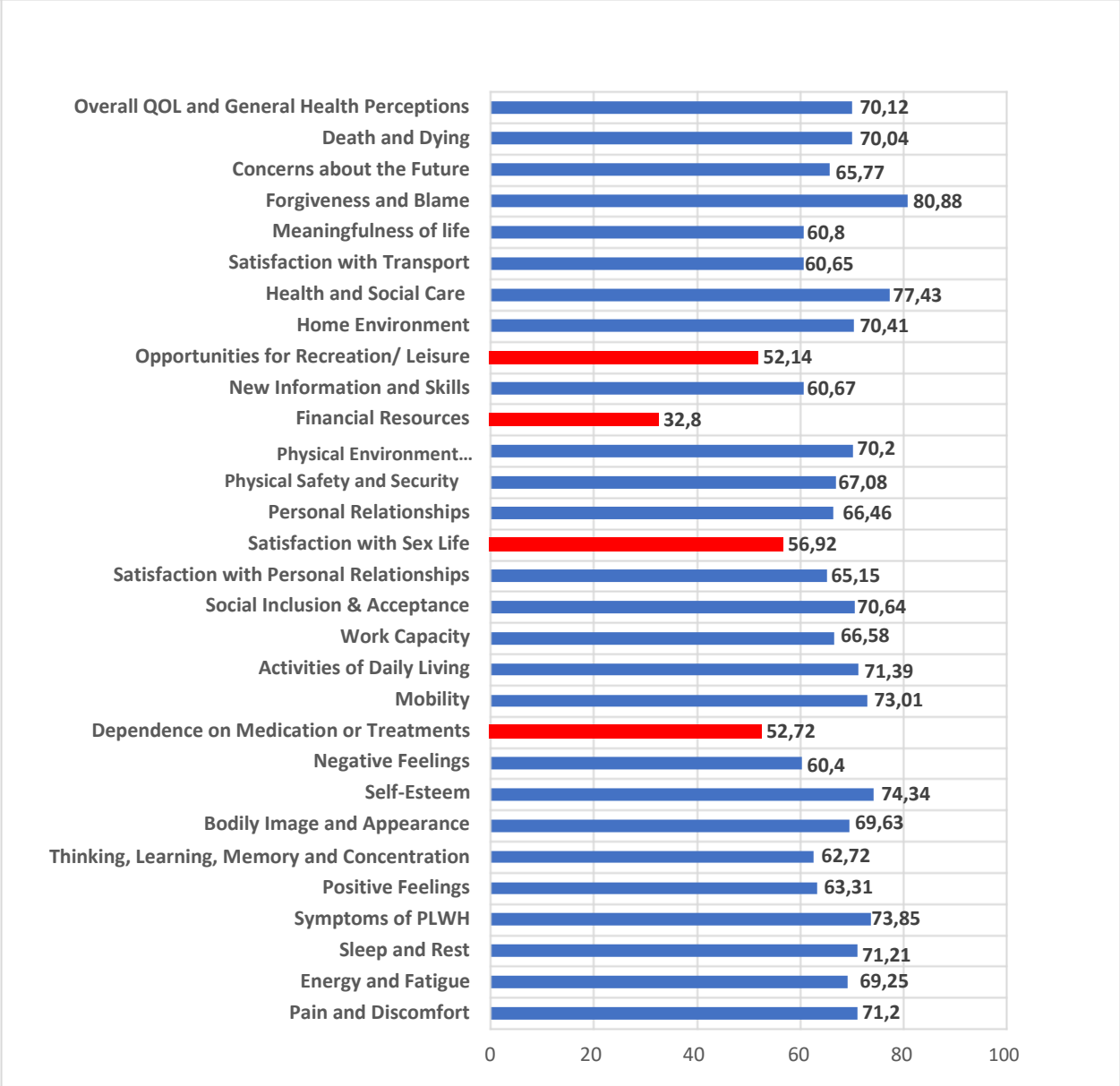

Figure 5: Mean Weighted QOL Scores of the WHOQOL-HIV BREF Items

4.1.6 The Mean Scores of HRQOL in Different Domains

Table 4.5 shows the mean scores for the Overall QOL and General Health Perceptions and six domains. In general, most respondents had good QOL (78.4%). The mean scores of QOL were highest in the Physical domain (15.4) and the lowest in the Environmental domain (13.8) and followed by the Social relationships domain (14.4).

Table 4.5: Scores for General QOL and 6 Domains (Mean ± SD)

General [a]QOL	3.8 (± 0.7)
Physical domain	15.4 (± 2.9)
Psychological domain	15.0 (± 3.3)
Level of Independence domain	14.6 (± 2.9)
Social relationship domain	14.4 (± 3.6)
Environment domain	13.8 (± 2.7)
Spirituality domain	15.1 (± 3.1)
General [b]QOL, n (%)	
Poor	107 (21.0)
Good	399 (78.4)
Missing	3 (0.6)

[a]General QOL score is derived from the questionnaire as the mean of question 1 (''How would you rate your quality of life?'') and question 2 (How satisfied are you with your health?'') based on the Users' Manual for Scoring and Coding WHOQOL-HIV BREF by WHO. It ranges from 1 to 5, with 1 corresponding to very poor QOL and 5 corresponding to very good QOL. [b] General QOL score of (3) was used as the cut-off point to define poor and good QOL.

4.1.7 Levels of General QOL (Poor or Good)

Bivariate Analyses:

Table 4.6 shows the socio-demographic and clinical characteristics of the sample by general QOL (categorized into two groups; poor or good). The overall results showed 107 respondents (21%) with poor general QOL and 399 respondents (78.4%) with good general QOL. The general QOL for three respondents (0.6%) could not be classified due to missingness. The results of bivariate analyses are provided in Table 4.6. Based on the p-values <10%, four factors were significantly associated with the general QOL (poor vs good). These factors include highest level of education attained (primary, secondary or tertiary), employment status (unemployed or employed), VL groups (VL < 400 copies per mL or VL > 400 copies per mL), and self-reported illness (yes or no).

Table 4.6: Socio-Demographic and Clinical Characteristics by General QOL (poor vs good).

General QOL	Poor	Good	p-values
Gender			0.419
Male	19.7%	80.3%	
Female	22.6%	77.4%	
Highest level of education			0.012
Primary	50.0%	50.0%	
Secondary	24.3%	75.7%	
Tertiary	13.0%	87.0%	
Employment status			0.069
Unemployed	22.9%	77.1%	
Employed	14.8%	85.2%	
BMI Categories (kg/m2)			0.730
< 18.5	21.9%	78.1%	
18.5 – 24.9	20.3%	79.7%	
25.0 – 29.9	26.5%	73.5%	
≥ 30	0%	100%	
Viral Load (copies per mL)			0.073
< 400	19.9%	80.1%	
> 400	29.4%	70.6%	
Feeling ill (self-reported)			0.001
No	18.3%	81.7%	
Yes	34.4%	65.6%	
Mean age (in years)	21.66	21.74	0.789
Mean CD4 Count (cells/mm^3)	586.38	597.37	0.778
Mean duration on ART (in years)	12.30	12.49	0.673

p-Values are from the Chi square tests for the categorical variables (gender, highest level of education, employment status, BMI Categories, Viral load, self-reported illness) and from two sample t-tests for the continuous variables (age, CD4 cell count, duration on ART) using a significance level of 0.10.

4.1.8 Multivariate Analyses:

A predictive model was developed by incorporating all factors that were associated with general QOL into the multivariable logistic regression (Table 4.7). Generally, odds for good general QOL increased with higher level of education and employment. And the odds for good general QOL reduced with unsuppressed VL (> 400 copies per mL) and self-reported “currently ill”. The odds for good general QOL increased by five folds (OR = 5.01, 95% CI = (0.28 – 89.8) and almost two folds (OR = 2.43, 95% CI = (0.14 - 41.2) when comparing tertiary and secondary education holders (respectively) against respondents with primary education.

Those employed had an increased OR = 1.61 (95% CI = (0.89 – 2.92) when compared to the unemployed group. The odds for good general QOL declined by almost two folds (OR = 0.59, 95% CI = (0.33 – 1.06)) amongst respondents with VL > 400 copies per mL compared to those with VL < 400 copies per mL. Also, the odds ratios for good general QOL reduced in respondents who were ill compared to those who were not ill (OR = 0.42, 95% CI = (0.25 – 0.70)).

Table 4.7: The odds ratios (and 95% CIs) of several covariates adjusted for the General QOL

Adjusted for	No. of patients	No. of patients with good QOL	OR (95% CI)	P-values
Highest level of education				
Primary (reference)	2	1	1.00	
Secondary	361	271	0.20 (0.01 - 3.58)	0.274
Tertiary	146	127	0.49 (0.28 - 0.84)	0.010
Employment Status				
Unemployed (reference)	398	307	1.00	
Employed	111	92	0.62 (0.34 - 1.13)	0.117
Viral load				
< 400 (reference)	441	351	1.00	
> 400	68	48	1.69 (0.94 - 3.04)	0.079
Feeling ill (self-reported)				
No (reference)	418	340	1.00	
Yes	91	59	2.73 (1.42 - 3.96)	0.001

The Goodness of fit using the ROC Curve:

Figure 6 presents the ROC curve for the fitted multivariable logistic model. The area under the curve (AUC) is 0.644. This AUC score suggests a fair predictive ability of the fitted model. In general, the AUC scores range between 0.5 and 1, with 0.5 corresponding to models with ‘poor’ predictive ability and 1 corresponding to models with ‘perfect’ predictive accuracy.

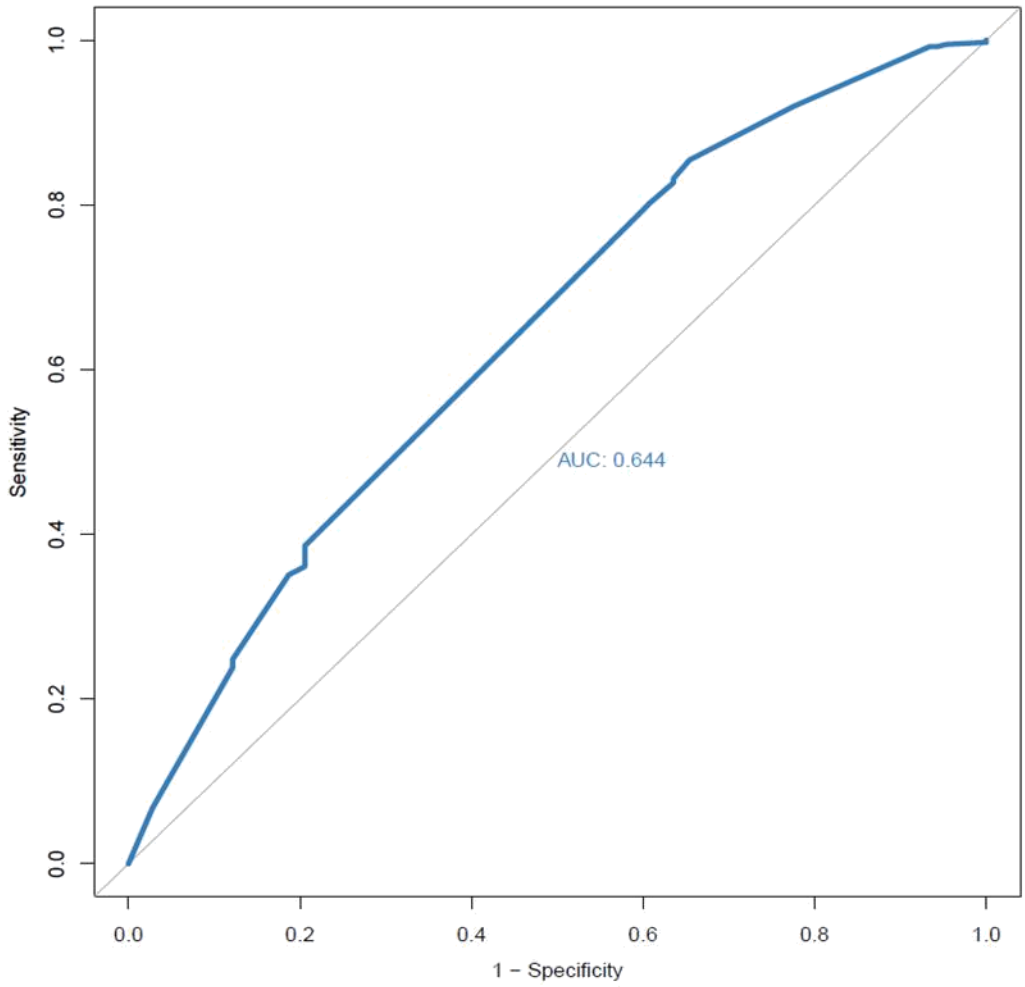

Figure 6: The ROC curve for multivariable logistic regression predicting the general QOL.

The mean score difference in six domains by adjusted covariates:

Factors included in the multivariable model were independently assessed with QOL scores in the Physical, Psychological, Level of Independence, Social Relationships, Environmental and Spiritual/Religion/Personal Belief domains (Table 4.8). At least two of the adjusted factors were significantly different against the Psychological, Level of Independence, Social Relationships, Environmental and Spiritual/Religion/Personal Belief domains. In contrast, the Physical domain only showed significant results ($p < 0.01$) when investigated against self-reported illness. The mean scores for VLs were insignificantly different across the six domains. Detailed results are provided in Table 4.8

Table 4.8: The mean score difference in six domains according to adjusted covariates.

	Physical Domain		Psychological Domain		Level of independence Domain		Social relationships Domain		Environmental Domain		Spiritual/Religion/Personal Belief Domain	
	Mean (SD)	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Highest level of education*												
Primary	17.00 (1.41)	0.26	12.50 (3.54)	0.01	11.50 (0.71)	0.00	9.50 (4.95)	0.03	10.50 (2.12)	0.00	15.00 (0.00)	0.15
Secondary	15.29 (2.91)		14.75 (3.30)		14.28 (3.00)		14.12 (3.57)		13.50 (2.73)		14.94 (3.06)	
Tertiary	15.71 (2.91)		15.65 (2.90)		15.32 (2.55)		15.07 (3.29)		14.68 (2.38)		15.54 (3.16)	
Employment status**												
Unemployed	15.32 (2.89)	0.14	14.79 (3.23)	0.01	14.44 (2.89)	0.07	14.30 (3.57)	0.37	13.74 (2.64)	0.15	14.92 (3.03)	0.01
Employed	15.79 (3.00)		15.76 (3.07)		15.02 (2.96)		14.64 (3.37)		14.15 (2.84)		15.83 (3.23)	
Viral load**												
< 400	15.50 (2.91)	0.13	15.03 (3.23)	0.58	14.59 (2.93)	0.65	14.43 (3.53)	0.42	13.88 (2.73)	0.30	15.15 (3.10)	0.52
> 400	14.91 (2.92)		14.81 (3.15)		14.42 (2.82)		14.05 (3.50)		13.51 (2.41)		14.89 (3.03)	
Feeling ill**												
No	15.68 (2.82)	0.00	15.27 (3.01)	0.00	14.76 (2.82)	0.00	14.84 (3.22)	0.00	13.95 (2.55)	0.04	15.34 (2.96)	0.00
Yes	14.23 (3.06)		13.74 (3.81)		13.70 (3.17)		12.27 (4.07)		13.29 (3.22)		14.05 (3.47)	

***** ANOVA performed ****** t-test performed

4.2. QUALITATIVE FINDINGS

4.2. 1 Introduction

This section presents the results of the in-depth interviews with a purposefully selected subsample of YALPH from those who participated in the WHOQOL-HIV BREF survey. In line with the sequential explanatory study design, the quantitative phase using the WHOQOL-HIV BREF instrument was completed, then followed by the qualitative phase using in-depth interviews. The in-depth interviews aimed to collect descriptive information and to interpret the statistical results obtained in the quantitative phase. The interviews also explored the lived experiences of YALPH and their perspectives on how their HRQOL could be promoted. The results are presented following the domains of the Ferrans Conceptual Model of HRQOL. A summary of the qualitative results is presented in Appendix 5.

4.2.2 Description of the Sample:

A sub-sample of 45 respondents (24 females and 21 males) ranging in age from 18-27 years participated in the in-depth interviews. The respondents in the in-depth interviews were purposely selected cases that manifested aspects of the themes that emerged from the quantitative phase of the study. All the respondents in the in-depth interviews were single although 3 respondents had live-in partners. Eleven respondents were in school (ranging from senior secondary schools to tertiary institutions) and 24 were employed. Regarding living arrangements, 10 respondents were renting, 1 lived in institutional care, 1 was in school residence and 33 were residing with their parents or other close family members. The respondents' duration on ART ranged from 5 to 10.6 years. Of the 45 respondents, 8 were parents with a range of 1-2 children. And 5 respondents had unsuppressed VL.

4.2.3 Biological Function:

Problems with HIV treatment: The quantitative results from the WHOQOL-HIV BREF showed that 13.8% of the respondents had unsuppressed VL. Additionally, a low QOL score was recorded on the WHOQOL-HIV BREF facet "dependence on medication and treatment" (52.72). Respondents in the in-depth interviews were asked how long they had been on ART and if they had any problems with HIV treatment.

Most of the respondents in the interviews (78%) did not have any problems with ART because they had been on it for many years. Secondly, most of the respondents reported being on once-daily ART regimens that were convenient with few or no side effects. The respondents were well aware of the therapeutic benefits of good ART adherence and the risks of poor adherence. In addition, the respondents were motivated to take their medicines well to remain healthy and physically fit to attend school, work, take care of their children (for parents), and to pursue their life goals. Most of the respondents were able to manage their medication independently. Other respondents' main sources of treatment support included their parents, close family members, HCWs and trusted friends and peers. The respondents' comfort with their treatment is exemplified in the following verbatim quotes:

"*I have been on ARVs since childhood and there are no difficulties that I am encountering."* Male, 21 years.

"Now that I have a job and my space and my things, I feel my life is OK and I need to take my medications well for me to remain physically fit and to continue working." Male, 26 years, university graduate, employed.

"Currently I am taking my meds very well. My viral load is going down. I do not need any reminders, everything is in me. I defaulted for 2 years and I fell very sick. I lost out on school. I don't want poor health to interfere with my goals in life. I am highly motivated to take my meds." Female, 19 years

"Attending Young Adults Support Group meetings, interacting with group leaders who are doing well on treatment helped me to change my mindset, the way I think and the way I look at things. I changed my attitude towards this infection and I started taking my medicines well." Male, 22 years

However, some respondents, including those who had suppressed VL at the time of the study reported occasional or longstanding problems with their treatment. The most commonly cited problem was poor medication adherence which the respondents associated with: fear of stigma, poor self-acceptance, being busy or away from home during medication time (work, school, sports, visiting) and forgetfulness.

Stigma was a challenge to ART adherence particularly when the respondents were in the company of people they had not disclosed to. Respondents missed ART doses when they were on school trips or visiting extended family members or at social events to avoid probable stigma. Others needed to create some excuses to explain their medication and clinic visits. One male respondent described his challenges with managing HIV stigma at school and the resultant effect on ART adherence:

"The problem started at tertiary where we live in shared rooms. Every semester I live with a different roommate. One semester I shared with a roommate and I didn't disclose so I didn't take my meds well. Sometimes I even forgot to take them after I procrastinated. My parents spoke to the Dean of Students who knows my status. He helped me to get a single room so it is easy to take my meds now." Male, 24 years

Poor self-acceptance was high among the respondents who had unsuppressed VL. The respondents said they had the outstanding question "why me"? In most cases, this question was linked to being the only person in the home or the only sibling among others being HIV infected and taking ARVs. As a result, those respondents had anger towards their biological mothers viewing them as the reason for their condition (HIV infection) which in most cases led to poor adherence to ART. One male respondent expressed his sadness with taking ART:

"The fact that I am the only person taking medicines at home saddens me all the time. I wonder why me of all my siblings? I can't find an answer to that question. I am the last born and the rest of my siblings are HIV negative." Male, 18 years

Discomfort regarding medication side effects was reported by 5 respondents including nausea, dizziness and sleepiness. Respondents applied many different

strategies to manage the side effects, including having naps during the day and taking the medicines with food or juice as described by one respondent:

"If the medicines didn't make me feel sick, I would be taking them very well. I am unable to take them in the morning when I go to school because I need to sleep and rest first. This is from the time when I was moved to second line drugs." Female, 22 years.

Some respondents reported poor or lack of treatment support from their families as a challenge to medication adherence. In such cases, family members perceived the respondent to be old enough to take care of his/her treatment independently. The respondents felt a sense of abandonment as they lost the crucial support from their parents and caregivers. There was also the feeling that their family members did not understand them or the situation they were going through, which resulted in poor family relationships and conflicts:

"You find that after someone has grown and reached my age, the parent concludes that this young person can take care of himself and then withdraws. We still need cooperation from parents. I think parents should communicate with doctors and at the same time they should talk to us about the ARVs at home." Male, 21 years.

"I am living with people who don't understand me and what I am going through. My sister says I am old enough and I should not be reminded to take my meds. Taking medicines every day is tough. I still need her support." Female, 20 years.

Some respondents had worries and anxieties about treatment failure, exacerbated illness and death. They felt that their lives were entirely dependent on medicines and if for some reason the medicine was not available, they would die as narrated by two respondents:

"Our lives are very vulnerable due to this HIV. Some peers that I knew very closely have died. I keep asking myself whether I will live a long life." Male, 20 years

"I sometimes have this thought crossing my mind that what if my body rejects medications or I developed those other illnesses that I have read about on the internet, what I will do?" Female 18 years

When asked what needed to be done to enable YALPH to deal with the treatment related problems, to adhere to ART and to achieve VL suppression the respondents proposed the following:

- HCWs should help YALPH to deal with illness and treatment-related worries and fears by providing in-depth information about HIV and ART including the possible side effects.
- HCWs should empower young adults to take care of themselves increasingly independently of their caregivers including taking their medicines and going for medical appointments alongside other activities of daily living (such as school, work, parenting and preparing nutritious meals).
- The Government of Botswana should provide more convenient ART regimens. For example, in the future if it becomes available, once a year ART regimens.
- The Government of Botswana should come up with new strategies for all patients who are studying or living abroad to access ART and other health care services where they are based and not to travel to Botswana for services.
- Botswana-Baylor and other service providers should hold adherence camps for YALPH, and also establish phone-based programs to follow-up and remind them to take their medicines and to go for medical appointments.
- The Government of Botswana should allow flexibility in the policy on nutrition and food support for YALPH. Age alone should not be the only criteria used to assess eligibility for food basket. The individual's social-economic status should also be considered. Food basket should be continued beyond 18 years to ensure good nutrition for YALPH and to support their adherence to ART.

"The youth in Botswana need to be helped to access nutritious meals to take with ARVs. The government must assess the background of the individuals and help them to continue with food basket even when they have reached the age of 18 years when the government food basket is supposed to be withdrawn. The medications are strong and to build the immune system one needs a healthy diet which we cannot afford in our homes." Male, 23 years

4.2.4 Functional Status:

4.2.4.1 Physical Functioning:

Functional status includes physical activity, energy levels, and performance of everyday tasks. The quantitative results from the WHOQOL-HIV BREF showed that the mean scores of QOL were highest in the Physical domain (15.4). The results also showed a statistically significant association between being ill and poor HRQOL. To explore these outcomes, respondents were asked to what extent they were bothered by any illness or physical problems that limited their activities of daily living. The responses showed that the majority of the respondents were clinically stable and did not have any illness or physical problems that interfered with their activities of daily living such as school, work, or home chores.

However, some respondents reported poor body image due to short stature, low body weight, prominent skin conditions (scars, flat warts, serious acne), body shape changes associated with lipodystrophy and physical disabilities. The two respondents with lipodystrophy reported being teased and stigmatized at school and in the community due to their unusual body shapes. In both cases, the medication associated with lipodystrophy had been changed, however, the effects had not been reversed by the new medication. The dissatisfaction with physical appearance and poor body image led some respondents into self-isolation to avoid people questioning or teasing them about their body structures or features. Four respondents shared their struggles with poor body image:

"I have a prominent scar on the face which I had since childhood and people always want to know what happened. It is a bit better now in form 5 because students there are older and they mind their own business." Male, 18 years

"I have lipodystrophy. I requested permission to wear pants in school instead of skirts in summer because other students were making fun of my small legs." Female, 19 years

"I have a terrible skin condition and people always ask what the problem is. I have to use heavy make-up to cover the scars on my face. I have spent my whole life answering questions." Female, 23 years

"My body structure affects me as some people say I am light and wobbly and they make fun of me. Sometimes I get angry and want to fight them." Male, 21 years

Some respondents reported a double burden of living with HIV infection and disabilities which included visual or hearing impairments, learning problems and other physical disabilities. The narratives showed that the disabilities and impairments affected respondents' functioning including mobility, self-care, school performance and reduced their employability. Respondents reported that the diagnosis and interventions for the impairments and disabilities came very late which affected their school performance and attainment. The following quotes demonstrate the functional challenges experienced by YALPH with disabilities and impairments:

"I have dyslexia, I can't read. I was told at school that I have a language processing problem. I failed form 5…. I am always wondering why things always go wrong for me. It is depressing when I see other people who are progressing well in their lives. The condition is very depressing when coupled with HIV infection." Male, 23 years

"I use Braille to read which makes all academic processes much longer for me. I fear it will be difficult in the workplace for me. Being discriminated for blindness and being HIV infected". Male, 19 years

"*I had a very serious attack of meningitis in childhood which affected my nerves and eyesight. I have been told by the eye specialist that my visual problems cannot be corrected by lenses. Poor vision has affected my life including school and home activities."* Male, 21 years

"I have a serious hearing problem which was not identified until I was in form 2. In class, I had to sit next to the teacher or else I wouldn't hear. I was taken to Tlokweng Resource Centre for assessment but I did not get the help until I had completed form 5." Female, 23 years

Four respondents carried exemption cards from the Office of the President, Disability Office to ease access to public amenities such as transportation, health care and others.

When asked what needs to be done to improve the wellbeing of YALPH regarding the challenges they faced with body-image, physical appearance, disabilities and impairments, the responses included the following:

- HCWs should counsel YALPH to boost their self-image and promote self-acceptance. YALPH should be encouraged and supported to eat a nutritious diet and do regular exercises to build their bodies and remain physically fit.
- YALPH should get appropriate ART adherence support to avoid serious illnesses that could result in disabilities and impairments.
- Ensure early diagnosis of visual, hearing and learning impairments and provide prompt interventions such as hearing aids and eye glasses.
- Provide YALP who have disabilities and impairments with information on their rights and the resources that are available to them through the government such as exemption cards, vocational or tertiary education, employment and other livelihood opportunities.
- The YALPH with disabilities and impairments should have an adult mentor to help them navigate the complex systems to access the services and resources that are available to them.
- Parents, caregivers and service providers should be equipped with basic sign language skills, for them to communicate effectively with YALPH with visual and hearing impairments.

4.2.4.2 Psychological Functioning:

4.2.4.2.1 Grief, Loss and Bereavement:

Some respondents reported grief, loss and bereavement resulting from the death of their biological parents, siblings, and other close family members. The death of a biological parent was reported by 19 respondents. The age at which the respondents lost their parents ranged between 02-21 years.

The narratives showed that the impact of parental loss on the lives of YALPH was profound and longstanding. Some respondents did not want to share their grief with anyone but rather kept it to themselves. Those who had lost a mother spoke of the loss of a strong emotional bond that goes with mother-child relationships; those

who had lost a father reported a lack of a father figure in their lives. Many respondents felt that living with HIV would have been much easier if their parents were alive.

The problems that respondents related to the loss of their parents included: worries and fear of death, poverty, the disintegration of their family homes and living with non-supportive relatives or in institutional care. Others experienced property-related conflicts, and some young mothers lacked child care support when they wanted to find a job or go back to school. The feelings of loss and grief were intense as described in the quotes below:

"I have a long story to tell about my life. I have only experienced the rough side of life. My mother is dead. My loving grandfather and grandmother are also dead. In my family, every fifth year a close family member dies. I am always worried that I may be the next to die." Female, 23 years

"*My mom, she passed away when I was doing form four. She got very ill and she passed away. The passing of my mom was the worst thing for me in my life. I didn't want to talk to anyone about it, so I haven't talked to anyone about it."* Male, 23 years

"*My mom passed away in 2013. She was the only person who encouraged me with medication and provided everything I needed. During this year's festive season, I was home alone and overcome by grief. The stress of losing my mother has affected my life including adherence to my medications*." Male, 25 years

"The way people I am left with think about me, sometimes I feel depressed and end up thinking about pasts, thinking about my mother, my life is meaningless. Sometimes I have suicidal thoughts." Male, 19 years

4.2.4.2.2 Disclosure Worries and Concerns:

Respondents were asked whether they had ever disclosed their HIV status to someone not a close family member or clinician and what challenges they had with disclosure. Some respondents felt no need to disclose their HIV status because they were healthy, they had sufficient support from close family members or they were not engaged in a romantic relationship. Some respondents considered their HIV status to be something within their private domain and there was no need to disclose.

"I have supportive, loving parents and their support is enough. I don't have to tell any other people about my status." Female 18 years

For the majority of respondents, the decision on when and how to disclose their HIV status to other people was "the most difficult thing to do" as far as living with HIV was concerned. The fear of being judged or rejected was the main reason for non-disclosure as described by two respondents:

"Opening up about my health at times is hard because I feel I would be judged and called names." Female, 25 years

"The biggest challenge affecting me as a young adult living with HIV is I am still afraid of disclosing myself to my friends and people around me. I sometimes feel like my friends will never talk to me again if I tell them I am HIV positive and now I told myself that I will not tell them." Male, 19 years

"No one knows about my HIV status. I don't want them to know because they would start stigmatizing me. I have a feeling that they would look at me in a different way which I do not want. Also, there are chances of them feeling pity for me. I do not want that in my life." Female, 21 years

However, 29 respondents had ever disclosed their HIV status to at least one person who was not a health care worker or other service providers. Most of those respondents had disclosed to a trusted friend or a romantic partner. Other people who were disclosed to included workmates, church mates and house/roommates. The reasons for disclosure were varied including the need for emotional or ART

adherence support, the conviction that the other person had the right to know or had asked and needed to be told the truth.

Disclosure to peers and friends:

Some respondents disclosed to a friend whom they considered trustworthy, accepting and supportive. In almost all cases, respondents who had disclosed to a friend reported positive outcomes citing increased emotional, social and adherence support. For example, two male respondents shared their experience of disclosure to a trusted friend:

"In senior secondary school, I had friends who drank alcohol and smoked cigarettes. One concerned female student approached me and talked about the negative consequences of bad peer groups in my life. She showed a good attitude and I later trusted her and told her a lot about my life including my HIV status. I felt the relief of having someone other than family to talk to openly. She has not disclosed to anyone and she continues to be a helpful friend." Male, 24 years.

"Some of my friends know about my HIV status. I did tell them about it after they realized that I was taking medicines every day. They asked me what the pills were for and I told them. They have grown close to me and their support is great. They are all good guys." Male, 23 years

However, in a few cases, disclosure to a trusted friend resulted in rejection and loss of control over who knew their status as described by two respondents in the quotes below:

"It is hard to trust. A very close friend of mine whom I told, disclosed my status on Facebook. I am currently trying to live with the fact that everyone knows about my status. She made a decision that was against my wish." Female, 19 years

"A close friend whom I disclosed to when we were in senior secondary school decided to tell my girlfriend about my HIV status. He was jealous and wanted to date the girl. The girl left me for him and it has been six weeks now." Male, 26 years

Disclosure to Sexual Partners:

Disclosure to a sexual partner was described as the most difficult thing to do by all the respondents, regardless of whether they had ever disclosed to a partner or not. All respondents spoke of the need to protect their partners and they were also aware of the legal implications of transmitting HIV infection to another person "knowingly".

However, some respondents were engaged in romantic relationships with a partner whom they had not disclosed to. The most common reasons for non-disclosure were that the relationship was new or not serious or due to a lack of trust for the person. Nevertheless, all the respondents who had not disclosed to their partners reported using condoms all the time. Those who had not disclosed reported the stress and burden of living in secrecy as described by one respondent:

"My biggest challenge is keeping the secret, having to hide my status from my boyfriend all the time. It stressful when I have to come up with excuses for coming for check-up, refill or to attend Young Adults Support Group meetings". Female, 25 years

Six respondents had sexual relationships with a partner who was also HIV positive to remove the burden of disclosure. In most cases, the respondents had met their partners at Botswana-Baylor Clinic or Teen Club or Young Adults Support Group meetings as described by one respondent:

"My girlfriend is also HIV positive. I love her and I will stick to her because she knows and understands my condition. She has helped me to change my behavior positively and to live well with my condition. We always talk about medicines, school, business, the future and other things." Male, 25 years

There were also positive outcomes of disclosure to sexual partners. In most cases, the partners tested HIV negative but remained in the sero-discordant relationship and provided social, emotional, financial and other support to the respondent. However, 11 respondents had experienced rejection following disclosure to a sexual partner. Some respondents had been rejected multiple times. Two female respondents recalled their sad experiences of rejection by partners:

"*My church encourages testing before marriage. I tested with my fiancée of two years. I thought he would understand since he was a Christian. He didn't. He tested negative and he was not willing to be with me anymore. But now my body tells me that I need to have sex. I don't know how I am going to handle telling a partner about my condition again*." Female, 25 years

"I had a long-time boyfriend who departed after I disclosed to him. I found another partner who is the father of my child but he also left me after disclosure. I have had frustrations with boyfriends and I don't want any more." Female, 22 years

All respondents spoke of having had discussions on disclosure with HCWs and at Teen Clubs and Young Adult Support Group meetings. However, the fear and lack of disclosure particularly to sexual partners was widespread among the respondents.

When asked what support YALPH needed to be able to deal with disclosure worries and fears, respondents proposed the following:

- Provide counselling to support individuals to accept themselves and their HIV status before they disclose to others so that whatever the outcome, they would be able to accept and live with it.
- In the case of romantic relationships, couple counselling should be provided to promote open discussions and prepare partners for disclosure.
- YALPH should attend support groups and camps with other peers to share experiences on how to disclose in romantic relationships.

4.2.5 Characteristics of the Individual

4.2.5.1 Education Level:

The quantitative results generated by the WHOQOL-HIV BREF showed a significant relationship between the level of education and HRQOL. To explore the association between education and HRQOL, respondents were asked about their school performance and or educational attainment. Eleven respondents in the in-depth interviews were still in school ranging from secondary schools to tertiary institutions.

Poor school performance and educational attainment were commonly reported by the respondents. Poor school performance and educational attainment were

attributed to illness and hospitalization (particularly in childhood); visual, hearing and learning impairments; illness-related worries and anxieties; HIV related bullying and teasing in schools; and some respondents didn't expect to survive to adulthood and therefore they did not study hard at school. Some respondents used to perform well in school, however, their grades dropped when they were informed about their HIV positive status. Some respondents were behind their class for age because at some point, they had discontinued school temporarily because of poor health.
School-related challenges are exemplified in the quotes below:

"*I was sick most of the time, I never had the time to read and I never had time for anything. Junior school was better than primary school. I could not focus on my school work. I didn't study hard. I didn't see the reason why to study hard. I didn't know I would live this long. I lost out in that way*." Male, 25 years

"*Since standard one I have always been a Ds student however hard I try. I am always desperate and frustrated by my grades. Sometimes I hate myself for that… I am a slow learner but in school, we are not given the chance to learn slowly. I prefer to do some training in a brigade and start working."* Male, 18 years

"*I am behind in school because I didn't attend school in 2016. I had Steven Johnson's disease and I was very sick. When I recovered, my memory was affected. Now I am struggling with Ds in form five."* Male, 21 years

Poor school performance and attainment accentuated feelings of personal inadequacy and worthlessness and created fear about the future. Such thoughts were exacerbated by the comments of teachers, parents and caregivers many of whom were anxious to see the respondent succeed academically; but who the respondents thought did not understand their school-related problems. In some extreme cases, poor school performance had led to suicidal ideations as reported by one respondent:

"*So there was a time when my grades weren't that good. So if my school grades were bad then I wasn't good at anything in life. I felt empty inside and sad. I didn't know how to solve it because I was honestly trying my best; other subjects were just so difficult. That is when I started having suicidal thoughts and I took a few attempts at ending my life.*" Male, 21 years

When asked what needs to be done to promote school performance and attainment among YALPH, respondents recommended the following:

- YALPH who have learning problems should be helped to access tutoring, special education classes and other remedial interventions.
- There should be an alternative school system that is less academic and focused on vocational or practical skills development that also assures success in life for youth who are not academically competent.
- The Government of Botswana should increase access to vocational training opportunities for youth who failed their form 3 and form 5 exams and are out of school to improve their outlook on life.
- Those who failed school should be supported to establish businesses and to gain financial independence.

"I have other talents. I can fix things. I want to go for training at Madirelo Training Centre or any other brigade so I can earn a living from fixing refrigerators, air conditioners and such equipment. If I have the training and the skills, and I get a job, the rest will fall in place." Male, 20 years

"All I can say is I'm not good with education and school. I tried my best to make it to form 5 that is where my education stopped. I plan on doing some catering business and I also want to be in the music industry because that is where my talent lies." Male, 22 years

4.2.5.2 Employment Status:

The quantitative results generated by the WHOQOL-HIV BREF showed a significant relationship between being employed and good general HRQOL. The results also showed that many YALPH were neither in school nor working. To explore the association between employment and HRQOL, respondents were asked about their employment status. Nine respondents reported being gainfully employed in full-time professional jobs which gave them financial independence and a sense of self-worth. Respondents who were employed felt motivated to take their medication well to remain fit enough to work as described by one respondent:

"*Now that I have a job and my space and my things, I feel my life is more meaningful and I need to take my medications well for me to remain physically fit and to continue working."* Male, 24 years

Other 13 respondents were employed in elementary jobs with low pay, long working hours, heavy workloads or poor working environments. Those respondents wished to be helped to access vocational or tertiary level training to gain technical skills and find beneficial employment.

"I feel hopeless. Starting my working life as a security guard is very depressing. I work from 06:00 AM to 06:00 PM for 6 days a week. I have no time for anything else after work. My salary is very low. After paying rent and transport and buying groceries for the month, I am left with nothing. I want to save money to go back to school to learn how to manage excavators." Male, 22 years.

"My current job as a farmworker is too heavy for my health. Watering the plants, carrying manure and harvesting is very heavy work for me. I want to go to a brigade to do a course which will help me find a better paying job." Male, 19 years.

Ten respondents were not in school and not working. The respondents attributed their unemployment to lack of post-secondary education qualifications, job scarcity, lack of work experience, disabilities and impairments and lack of capital to establish businesses.

"*Because of poor performance during my school years, I did not make it to tertiary and I do not have the qualifications needed to find a job. I am doing nothing and I am always bored at home. I need access to job opportunities where I can use my own hands such as sell in shops or work at construction sites. I am fit and I can use my hands to work. I need to make some money, to provide for myself and also sponsor myself for a course. My mother who provided everything died in 2013. Now I have to provide for myself."* Male, 24 years

Some respondents who had vocational or tertiary level qualifications were unemployed because the job market was saturated or the jobs required work experience which they lacked. Unemployed respondents had financial stressors and could not meet their basic needs. They had feelings of embarrassment and worthlessness because they could not provide for themselves or their children. The idleness was stressful and often led to risky behaviours such as alcohol abuse.

"*I am not working and I am idle. I end up associating with people and groups that I do not belong to. I wish Baylor would have programs for young adults like me who are not working at least for them to keep busy to avoid doing bad things. They should also teach us and empower us to create jobs for ourselves if we cannot be employed."* Female, 21years

The following were respondents' proposals on how to address the problem of unemployment among YALPH:

- YALPH need to be provided with information on available employment opportunities and other youth development schemes provided by the Government of Botswana and or private sector initiatives.
- The Government of Botswana should increase preferential job opportunities targeting youth who are neither in school nor working.
- The Government of Botswana should expand opportunities for technical and vocational training; create a bridging program from unskilled to skilled employment.
- Provide training and mentorship to build the confidence of YALPH in job seeking and the establishment of businesses.

"The government should not issue money or other handouts but put in place lasting solutions through job creation and education. The government should equip us with business skills and also help us to access youth empowerment schemes such as government loans so I can improve my life and that of my family." Male, 22 years

4.2.5.3 Future Related Worries and Concerns:

Worries and concerns about the future life were elicited with the question "how do you see your life in the future?" and "Is being HIV positive a challenge to your future?" Most respondents (32/45) had a positive outlook on the future. They were confident that being HIV positive would not affect their prospects for the future. Those respondents hoped to be in good health due to the efficacy of ART; to complete school successfully and find well-paying jobs or establish business and be financially independent; establish their own homes, marry and have children. Respondents' positive perspectives of the future are exemplified in the quotes below:

"All in all I'm very positive about life. I'm positive that great things are going to happen to me. I find life to be great in a way even though there are a lot of negative things surrounding my life. Good things come to those who wait." Male, 22 years

"I would like to start a beauty therapy business. I need to first go for apprenticeship and then apply for financial support from government youth empowerment schemes." Female, 23 years

"I see a lot of positivity in my life, so much to do. It seems impossible but with God, I know it is possible. To me being HIV positive is not a big challenge at all. I want to manage a big company, and hire my two friends to help them reach higher levels. I want cars, big houses. I will push myself to achieve." Male, 24 years

However, some respondents had worries about the long-term availability of free ARVs provided by the Government of Botswana. They felt that their lives were entirely dependent on medicines and if for some reason the medicine was not available, they would die as narrated by two respondents:

"Our lives are very vulnerable due to this HIV. Some peers that I knew very closely have died. I keep asking myself whether I will live a long life." Male, 20 years

"I have a fear of the future without ARVs because my life is entirely dependent on medicines. If for some reason I don't have the medicines or they give me side effects and they don't work anymore what will I do?" Male, 22 years

Some respondents were worried that they would not find employment in the future because of poor school attainment or their HIV status would be used to exclude them from job opportunities such as joining the Botswana Defence Forces. There were also worries of potential stigma in future workplaces if people got to know about their HIV status.

"The dream of being independent in my own home and earning a living is not going to be easy because I have failed my form 5 and not gone to tertiary." Male, 19 years

"The challenges are very many because when you go to work, people will ask you about your check-ups and it is hard to tell others about it. It is the same as when you are a student." Female, 22 years

"*I am worried about what will happen if I want to get a job because some employers do medical tests before employment. If they find out my condition, will I get the job or they will leave me out for that reason? That is a big concern in my life. They should allow us to work. I am not sure of the current situation but I hope they do not discriminate against us."* Male, 21 years.

"I have studied with many people who are working in the medical field. I am worried that if I leave Baylor and go to other clinics I will face the challenge of trusting and receiving services from health care workers who know me personally." Male, 23 years

Some respondents were worried about financial independence after the death of their parents or caregivers. Those who lived in institutional care were worried about how life would be when they age out and go back to their families of origin.

"I am always depending on other people such as my parents. I face an uncertain future with HIV especially when my parents are gone. Will I manage without them?" Male, 22 years.

The desire to marry and have their children and families was spontaneously brought up by most of the respondents. However, there were worries and uncertainties about finding an accepting partner and how they would disclose their HIV status to them. Others were worried about how they would disclose their HIV status to their children in the future.

"I have a boyfriend of three years and I haven't disclosed to him because we use condoms all the time. I fear how the future is going to be when I have to disclose to him and to have children. I do not want my kids to be HIV positive like me." Female, 22 years

"I see my life as being very difficult because of my status. I have a fear that I won't be able to be married or have children. I wonder whether I will find the right partner who will accept my status, marry me and have children with me." Male, 26 years

"Sometimes I feel very lonely and I think I will need a boyfriend in the future. What am I going to tell him? I don't know how to start. I need someone to guide me." Female, 22 years

Respondents were asked what support YALPH needed to strengthen their outlook on the future. Responses included the following:

- YALPH should be counselled and assessed to evaluate how satisfied they are with their lives. And if they are not satisfied, they should be supported to come up with their goals for the future and set strategies on how to achieve them.
- HCWs should counsel and support YALPH to adhere to their medicines and to be physically fit to achieve their future goals.
- Create employment and business opportunities for YALPH. Schools, HCWs, and other service providers should provide YALPH with information and support to access government and private sector youth empowerment schemes to enhance their wellbeing and their hope for the future.

"Engage with us young adults more. Get us to know what opportunities are available outside the clinic, in the government and the private sector. Select days where we can all sit and encourage each other about the future. Young adults who are married and working and successful in life should be invited to talk to us." Male, 23 years

4.2.5.4 Individual Coping with HIV:

Respondents were asked how they were coping with HIV infection, what helped them to cope, and whom they looked up to for help. The narratives showed that respondents used a range of coping strategies both adaptive and maladaptive coping to live with HIV infection. The coping strategies reported by the respondents were categorized following Carver's Brief COPE Inventory Model 2 (Carver, 2013) shown in Figure 7.

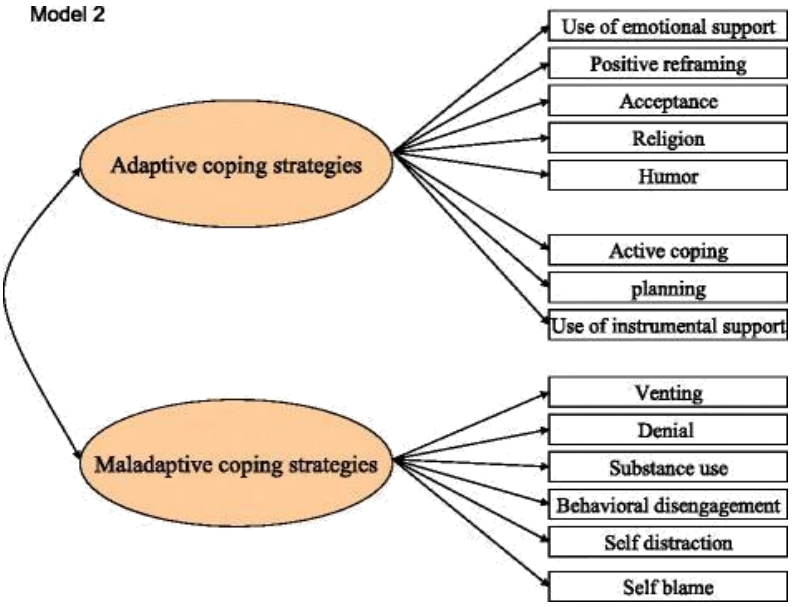

Figure 7: Brief COPE Inventory Model 2 (Carver 2013)

4.2.5.4.1 Adaptive Coping Strategies:

1. Use of emotional support (getting emotional support from others): The majority of respondents (89%) indicated they were able to come to terms with their HIV status over time because they received reassurance, encouragement and emotional support from their families, HCWs, romantic partners or trusted friends. Support from peers at Teen Cub and Young Adults Support Groups at Botswana-Baylor were commonly identified as group-level sources of emotional support:

"I never had any problem accepting my status so the love I got from my parents helped to accept my status. My parents are my best friends. We always sit and talk, I share my feelings, they listen to me and I listen to them. As a result, I never had anger so I think parents should provide love and when the child comes to Baylor, the staff should continue with the love and support. And the message from the parents and the Baylor staff should be the same." Male, 24 years

"I have disclosed to my two childhood friends. I sat them down and I told them that I'm HIV positive and according to the doctor I got it from my mother. The first thing they told me was you are not alone. They gave me support and they have been there since then. Even if I send them a text or message on Facebook or WhatsApp

saying I have a headache they would say "consider your health first, a minor issue should go to the doctors." Female, 21 years

2. Positive reframing (making the situation seem more positive): The narratives show that some respondents (25%) were coping by replacing negative, self-defeating thoughts with positive and affirming feelings. For example, some respondents with the support from their families, school teachers and HCWs, were in good physical health, had excelled academically and or were employed which gave them a sense of normalcy. Some respondents felt advantaged, in that due to their HIV infection, they were connected to health care facilities and were in contact with HCWs and their health was continuously monitored as compared to individuals who went for health care services just once in a while.

Some respondents had accepted their HIV status and even perceived some long-term beneficial consequences of their condition. Being HIV positive was a motivation to the YALPH to work harder in school, a reason to avoid negative peer influence associated with drugs and alcohol abuse, and to eat nutritious meals in order to remain healthy and strong.

"I can say everything that has happened around my life when I was a child built me; it gave me a stepping stone to my future. I got to learn a lot of things that most people my age haven't even experienced. Some of them experience them when they are much older but I got to experience a whole lot of things when I was young. I learnt very early that this is a condition I cannot change. I told myself I want to live life and change my living situation. So I set my life goals very early and very high. I decided to take my medicine the way it is prescribed and come for my regular check-ups. It was hard at first but once you get to understand HIV/AIDS you start to know that I'm not different, yes I have HIV/AIDS but it doesn't describe who I am." Female, 19 years

3. Acceptance (accepting the reality of HIV infection and learning to live with it): The respondents' narratives showed that the majority of respondents in the in-depth interviews (88%) had accepted their HIV status. What helped them to accept their HIV status included: continued education and counselling by HCWs as part of clinical care; and open communication and strong support from parents and close family members. Some respondents said they did not believe, so they re-tested, confirmed their HIV status and then started to take their medicines as prescribed. In extreme cases, some respondents had accepted after falling very sick and being hospitalized or their VL having been very high and CD4 cell count very low consequent to poor adherence or defaulting from treatment.

"I accepted when I was in standard six and I got information that my parents died from HIV. That is why I don't have a problem taking my medicines and going for check-up." Male, 19 years

"I feel fine, nothing has changed in my life. There is more to life than being positive. I would not let my status define me. I am coping well. Accepting my status was key in coping with being HIV positive." Male, 22 years

"I tested by myself when I didn't believe it. I was just told and I never saw the results. I re-tested at some group called BORNUS, and it was true like I was positive. Since then I believed that I was positive and I started to take the meds well." Female, 26 years

"HIV to me is like a flu that doesn't go away. It feels like normal flu; it is not painful but it is there. I never consider it something very serious because I take my medication. I am healthy, I eat well, I'm at school, and I'm leading. I'm not skinny, you don't see it written on my face that she is HIV positive unlike when you have flu you cough then someone would know she has flu. Also, I have access to professionals who can inform and guide me on many things beyond my condition." Female, 19 years

However, a few respondents (9%) had not fully accepted their HIV status but they just got used to the situation or they were just suppressing their feelings about HIV

and just taking the medicines and following what the HCWs and caregivers wanted them to do (helpless behaviour):

"*As a young adult with HIV, I have no choice I am bound to live with this virus for the rest of my life. So if I am willing to live, I should do exactly what the doctor says*." Male, 22 years

"I wouldn't say I have accepted myself but I just got used to the situation. Not to say I have accepted myself. It always comes back, time and again but I just got used to living like that, to take my medicines as prescribed to live on. It is still a burning issue to me and I still have a lot of questions which I know I won't get the answers for… so I have to keep taking my meds and see what the future presents to me." Male, 18 years

4. Religion (praying and spiritual beliefs. Getting the strength through belief in God): A few respondents (30%) reported spirituality, religion and belief in God as a source of hope, strength and encouragement to cope with HIV infection. Those respondents attributed their good health, longevity and all other achievements to God. The narratives showed that respondents put trust in God to help them manage the hardships in their lives while others attended church consistently and received spiritual and emotional support from their pastors, church mates and peers. Others found religion to be a source of healing from the anger and blame they had towards their parents and helped them to have a positive perspective on life. When others had illness-related fears and worries, they prayed or listened to gospel music.

"I am a member of the youth praise and worship group at my church we are into gospel music. I have told them about my condition. They are always there for me, encouraging me to go to church and they told me these overload problems in me I can offload them to God. They are always praying with me and they are there every step of my way. So we always comfort each other through prayer and music." Female, 26 years

"I am a child of God because I am a Christian. If you are a child of God, you should always walk with power and hope and nothing should steal your peace. My God has given me peace, it is in me and my role is to take that peace and use it. I do that all

the time that is why now I can say my life is settled I can live with the issues in my family and I can take my medicines well." Female, 22 years

"God has many ways of rescuing His people and He used Baylor, the services of Baylor to reach out to his people. So Baylor is a gift from God that came at the right time. I like the fact that at Baylor every morning before service we start with prayer. I believe that is what made Baylor be what it is and it is a very good clinic. I thank God because Baylor has helped me of which if Baylor was not there, maybe I would have lost my life." Male, 21 years

5. **Humour (making fun of the situation, irony):** Some respondents (13%) used humour as a coping strategy. They reported that they were stressed when they first learned of their HIV status. However, over time they had accepted and they were able to cope by making fun and joking about their situation as reported by one respondent:

"I learned about my HIV status 12 years ago. On that day, my entire world collapsed. Later I came to grips with what I am and what is going on inside me. Now it is being okay; I have come *to live with it. I view it childishly like maybe I'm like a robot that always has to take its batteries for recharging. Every time I take my pills so I view it in that way and it doesn't seem so sad anymore."* Male, 23 years

One female respondent made fun of her stature:

"*When I start working, the first things to buy will be some more height and bums."* Female, 18 years

6. Active-coping (doing something about the situation): The narratives showed that almost all respondents (91%) were taking action and had plans to remain in control and in good health mainly by adhering to ART and keeping their HIV status confidential. Choosing to keep their HIV status confidential and disclose only to trusted people and avoiding possible stigma and rejection from others was a major protective and active coping strategy that nearly all of the respondents adopted. In addition, all respondents had positive perceptions of the benefits of ART to their health and on their wellbeing. Even those who experienced drug side effects made

efforts to minimize the side effects such as taking medicines with juice or food as exemplified by the following quotes:

"I came to Baylor in 2004. Before that, I was in and out of the hospital, very weak. I never used to go to school at that time because I could not sit without being supported. After starting the treatment, it changed my life, and right now when I walk in the streets no one can tell whether I am HIV positive or not. So I think ARVs cover the difference between someone who is positive and who is not positive. It has helped me to live life like everyone else so ARVs are very important and I will continue to take them very well." Male, 22 years

"These meds are good because even when I am with someone who is not infected there is no difference. There will be a difference only if I stop taking them. This means when I take the meds properly I can do a lot of things; I can live for long as compared to someone who doesn't know their status. ART is very useful when you take it well and if you don't that's when there is a problem." Female, 26 years

7. **Planning (coming up with a strategy about what to do):** The narratives showed that most respondents (82%) coped with HIV infection through self-determination and planning. Essentially, respondents had adjusted to being HIV positive and they had taken a stand in life to take care of themselves and live a good life. Respondents spoke of persevering, considering available opportunities, willing to act, strategizing, and taking steps to deal with the problems they were faced with to improve their wellbeing and achieve future goals. For example, those who were out of school planned to acquire relevant job skills to increase their employability. Others planned to seek funding from youth empowerment schemes to establish businesses and to fight poverty.

"I have big dreams that I want to accomplish in my life. Right now it is me and school; it is the only thing I am focusing on. Back then I didn't have time to focus and I failed my exams but now I have a second chance. I want to see myself somewhere, so school is the only way. I am also going to a driving school; I want to get my driving license by the end of this year." Male, 21 years

8. Instrumental support (seeking advice, help, or information and learning from others):

The narratives showed that some respondents (87%) were coping through instrumental support through seeking and receiving advice, help, or information from family members, friends, peers and HCWs. All respondents had a very strong relationship with HCWs at Botswana-Baylor who were always available to provide continuous advice and information on how to deal with both clinical and psychosocial challenges:

"All I want to say is that Baylor is an organization that plays a good role in someone's life because they are there and they support you. They are not only focused on your medication but also on your health generally. Also in Baylor, it is not only doctors that you see, but there are also people like social workers, psychologists, peer educators and others. If you have a problem, they can support you and eventually you find you can live with this condition very well." Female, 21 years

"Health Care Workers at Baylor always talk and emphasize the importance of education. They always asked how is school, how was I performing and then I remember they told me health comes before education. So you cannot go to school if you are not well so you need to take care of your health so that you may be able to perform well in your education. They always encouraged me a lot to work hard and they always wanted to see me go far and they always wished me well in my studies every time I came to the clinic." Male, 23 years

Teen Club and Young Adults Support Groups were cited as highly impactful sources of instrumental support particularly the bonding and learning from other youths who had similar experiences with them:

"I sometimes need advice from someone with the same problem or status on things like medication adherence because they understand what I am going through." Male, 18 years

"Young Adults Support Group is not only about leisure and entertainment; you get to learn a lot of things plus it is a great way to meet other people like you in a way. Our situations are not the same but there is some similarity. You get to meet with so

many young people who can give you some essential information, be a motivation to you and who can inspire you to be different and to do great things." Female, 19 years.

4.2.5.4.2 Maladaptive Coping Strategies:

9. Venting (*expressing negative feelings*): Some respondents (37%) expressed anger and resentment towards their biological mothers and fathers for infecting them with HIV as expressed by two of the respondents:

"For the past ten years, since I was informed about my HIV status, I have been angry. I have wanted to know why me of all my six siblings I am the only one who is HIV infected. I sometimes spend nights out and drink alcohol which helps cool my anger. I do this mainly to make my mother angry for infecting me with HIV. I no longer want to see or deal with her." Male, 22 years

"Sometimes I cry with anger when I think of my mother that she didn't protect me from HIV, unfortunately, she is dead. Why did she breastfeed me, why did she not take ARVs to protect me? I am the firstborn and I am the only one who takes meds. I sometimes ask myself why. It is not fair for me to be the only child on treatment and having HIV." Female, 18 years

For some respondents (11%), their anger was exacerbated by the perception that HIV infection limited, restricted and controlled everything important to them and prevented them from enjoying life as other young people did:

"Having this virus has imposed big restrictions on me. It dictates what I drink, when I eat, when I go home, the kind of woman I will marry. I had a dream of being a soldier but that will never be because there are restrictions on HIV infected people joining the military in Botswana. HIV limits choices in life." Male, 22 years

"As an HIV patient, sometimes I cannot do some life activities such as visiting with friends because every day I need to take medicines. Sometimes I feel like a lot of big opportunities are just passing by as I grow up because of my situation. Growing up and accepting myself with this condition has not been easy." Male, 21 years

When asked how they could be helped to deal with the anger and negative feelings, respondents proposed that HCWs should facilitate open dialogue between parents/caregivers and the youth to deal with the unanswered questions that they (youths) may have.

10. Denial (refusing to believe that it is real or true): A few respondents (7%) still had feelings of denial or doubt of their HIV status. One 18 years old male who was diagnosed with HIV five years earlier was still processing the results and he had not yet accepted his results. In addition, two respondents were tested for HIV when they were still very young, they had been healthy all along and they had never seen their HIV test result or documents. To them, there was no evidence of being HIV positive. However, all three respondents took their medicines well and their VL was suppressed:

"*I can't describe how I feel about being HIV positive. It's a sort of thing you don't think about all the time. You try to push it aside and don't think of it."* Male, 20 years

Asked what support they needed to deal with denial, the respondents recommended that HCWs should provide detailed information about HIV and AIDS and answer all questions that youth may have about their condition and where necessary refer them for a re-test.

11. **Substance use (*use of alcohol and other drugs to feel better*):** In an attempt to cope with HIV infection and the related stress and worries, some respondents (11%) spoke openly about drinking alcohol to think less about their condition as described by one respondent in the quote below:

"*I do not work and I am bored the whole day. So some evenings and over the weekends I go out partying with my cousins and friends. Taking alcohol helps me to forget my problems. But I do not drink too much because it is not good with medicines."* Male, 24 years.

12. **Behavioural disengagement *(giving up the attempt to cope)*:** this coping strategy was not reported by any of the respondents in this study.

13. Self-distraction (*doing something to think about it less*): The narratives showed that to cope with HIV infection, many respondents (56%) engaged in avoidance coping or self-distraction. Respondents either became engrossed in school, work, church, social media, sports, or watching television and listening to music to think less about their condition. Others just avoided talking about HIV as much as possible. Respondents reported that even within the close family members, apart from reminders to take medicines and go for check-ups, discussions about HIV were rare.

"My school is very interesting, most of the time I am with my friends whom I live with at school, or I go to play chess. I go to sports tournaments and also I like to sit around and chat with them or be at the fellowship or library, which is what I do most of the time. It keeps me busy and I do not dwell too much on my situation." Male, 21 years

"I'm a funny person, I like comedy, I like laughing a lot, and I like being entertained. I do not focus a lot on my status. I am also a hard worker when it comes to school or anything like problem-solving. I like to work hard and try my best to solve issues diligently. I think a lot about the future, I think a lot about what the future holds for me and what I can do to make myself happy in the future." Male, 25 years

"My grandfather does a good job to remind me about taking my medicines and going to the clinic for check-up. But I don't want it to be a constant topic of discussion. It saddens me. So I throw myself into all other talks about other things and not about HIV." Male, 19 years

14. Self-blame: Some respondents (15%) blamed themselves for the difficult situation they were in. For being perinatally HIV infected while their siblings were not; for not taking their medicines as prescribed and achieving VL suppression; not putting emphasis on their education and failing exams; not taking their medication well and giving birth to an HIV infected child; or being generally unlucky.

"I used to have many questions of why me. I am the unlucky child comparing myself to my siblings who are not on treatment. I feel there is something very wrong with me. I can't understand it. Everything I try fails. I am always anxious about what is going to happen in the future." Female, 19 years

"I often get angry with myself if I work hard and don't get the results I wanted. When I don't do as well as I hoped to, when I don't take meds as prescribed, I often get upset with myself." Male, 21 years.

"I sometimes feel guilty and blame myself for not taking my meds well and for infecting my son. But I try to dismiss those feelings. I fear my son may blame me for infecting him and facing that situation worries me." Female, 18 years

4.2.5.4 Transitioning to adulthood: Young Parents

The social-demographic information generated by the WHOQOL-HIV BREF and the review of the medical records showed that 14% of the respondents were parents (range 1-3 children). Eight respondents (2 males and 6 females) in the in-depth interviews were parents. Two of the mothers had HIV positive children. To explore the effect of parenting on the HRQOL, respondents in the in-depth interviews were asked to share their perspectives and experiences regarding parenting.

Most of the respondents said that they would like to be parents someday. However, some said they were too young to take that step, or they were still busy with school, or they needed to be financially established before making that decision. The respondents acknowledged that because of their HIV status they needed to be cautious when making parenting decisions.

The respondents who had children reported that parenting was fulfilling, it gave them a sense of self-worth, and the motivation to take their medicines well to be healthy and to provide for their children. Some of the young parents were satisfied with the child support they received from their family members and or partners. However, most mothers were unemployed and they reported challenges with single parenting, unsupportive fathers of their children, and for some, lack of support with child care where they wanted to go back to school or find employment. Parenting was

associated with a lack of time for leisure and recreational activities. Some of the mothers were supported through Government-provided services including public works employment (Ipelegeng) and or nutritional support for the children through Child Welfare Clinics in the communities.

"I love my children very much. They give me a reason to live. I take my medicines well so I can take good care of them. But parenting without a job is difficult. My children's father does piece jobs in welding and he gives us some money sometimes. He loves his children but he is not able to provide for them." Female, 23 years, a mother of 2 children.

"Even if they (fathers) do not have money, they should just show love and care for their children." Female, 24 years

"*Help me find a paying job where I can get reliable income to buy food and cater for my 2-year-old child."* Male 24 years

Two young mothers who had HIV positive children reported feeling guilty and blamed themselves for infecting their children. They also had challenges balancing their own medical needs and those of their children:

"I was pregnant and was shy to be seen by people at Baylor Clinic. So I stayed away. I have a seven-month-old son who is also HIV positive. I do feel a bit responsible." Female, 27 years

"I sometimes feel guilty and blame myself for not taking my medicines well and for infecting my son. But I try to dismiss those feelings. I fear my son will blame me for having infected him and living through that situation worries me." Female,18 years

When asked what support the YALPH needed to promote their wellbeing as parents, the responses included the following:

- Young mothers need to be informed about the services and resources that are available to them through government and other organizations and to be helped to access them. Some of the respondents wished to go back to school to complete secondary school, attend vocational training, or tertiary education.

- The young parents also wished to be helped to find meaningful employment for them to meet the basic needs of their children.
- The young mothers proposed the formation of peer support groups for the exchange of knowledge and experiences on parenting. The Botswana-Baylor Young Mothers Support Group was cited as a beneficial forum for knowledge sharing with peers.
- The young mothers called for counselling or mentorship to increase their abilities to manage relational stress and conflicts with unsupportive fathers of their children.
- The male respondents called for male-focused sessions to teach them about fatherhood and parenting. This proposal was supported by young mothers who recommended that young men should be empowered to assume their fathering responsibilities and not to leave all parenting responsibilities to the mothers of their children.

4.2.5.5 Transitioning to adulthood: YALPH Aging out of Institutional Care:

The social-demographic information generated by the WHOQOL-HIV BREF and the review of the medical records showed that some YALPH were living in or had transitioned out of institutional care. Three respondents shared their experiences of living in institutional care. One male respondent aged 19 years was living in institutional care and completing vocational training. The respondent was satisfied with the care provided by the social workers and other personnel at the care institution. However, he had stressful and traumatic experiences with his family of origin before he was taken to institutional care. He had worries about the future when he would age out of institutional care:

"My brother and I have lived there since childhood. I have no idea what will happen to us when we have to leave because we have no one to go back to. It is a disturbing situation." Male, 21 years.

Another male respondent aged 26 years exited from institutional care after completing university education. He entered institutional care as an orphan aged 9 years after the death of his parents. He was given a one-year notice and some counselling in preparation for exit from institutional care. The hardest part of exiting

from institutional care was leaving the friendships he had created there and taking care of his treatment including keeping his medical appointments. Although he did not have a concrete plan before exiting institutional care, he had been helped by the social worker to find internship placement in a community-based organization that later hired him:

"One of the greatest struggles I faced after exiting institutional care was figuring out how to take care of my medicines, go to work, prepare meals, and many other things. I loved the freedom however that freedom soon turned to loneliness and sometimes, even fear. I didn't know what I wanted in life and trying to figure it out on my own was hard especially when I didn't have parents or someone to guide me." Male, 26 years

One 27 years old female respondent had aged out of institutional care at the age of 23 years. She had a university degree however she was still unemployed. She had established a small business with her sister who had aged out of institutional care as well. She was given a few months' notice before exiting from institutional care. However, she owed a lot of her success in transitioning out of institutional care to the counselling and support she received from the institution's head. The counselling she received emphasized reintegration into her family of origin, retention in care and continued ART adherence, finding employment and establishing independence. There were also a series of sessions she had attended which focused on life skills including financial management, business literacy, managing relationships, food and nutrition, parenting and many others.

However, all of her teenage and young adulthood she had struggled with depression for which she was still seeing a psychologist. By the time of the interview, she was able to take her medicines very well and go for medical appointments independently. She benefited from the counselling and preparations she received before her exit from institutional care. However, she felt there were other things she could have been prepared for as reflected in her narratives:

"Things such as Omang (identity card) are things you don't put a lot of attention to until you need them. The other thing is the lack of preparation for dealing with family

issues. My sister and I struggled and still struggle to claim back our parents' house and property from our uncle and his family. Nobody ever talked to me about that, let alone helped me prepare for it." Female, 27 years

When asked what needs to be done to prepare YALPH as they transition from institutional care back to their families of origin or independent life in the community, the 3 respondents proposed the following:

- YALPH should be allowed to remain in institutional care until they find a job or until they can live independently. Youths should not be forced out of the institutions before they are ready to live independently.
- Youth should be involved in the planning and decision-making well before they age out of institutional care for them to have a say in what they want to do with their lives. They should be consulted on whether they want to go back to their families of origin or to live independently in the community.
- After exiting from institutional care, youth should be given support to find jobs or financial help to establish personal businesses.
- The youth need a mentor to give them information about available resources and supports and to help them to navigate various systems to access education, employment, and other services.
- Services such as counselling should be continuously provided to youths who exit from institutional care to empower them to continue taking their medicines well and to work through past traumas and current stressors.

4.2.6 Characteristics of the Environment:

The characteristics of the environment theoretically include all of the individual's surroundings; including the social and physical environment. The characteristics of the environment that were explored in this study included HIV-related stigma, social support and financial resources. The quantitative results from the WHOQOL-HIV BREF survey showed the mean scores for general QOL were lowest in the Environmental domain (13.8).

4.2.6.1 Social Support and quality of relationships:

Family relationships and support:

The majority of the respondents described their family relationships as good, healthy, loving, caring and supportive. Families provided emotional support; treatment support and encouragement; financial support; school support; general encouragement; and a safe home environment. The orphaned respondents recounted the strong support they received from their family members in the absence of their biological parents.

"After my parents passing away, my aunt adopted me and I went to live with her. She treats me like her own son and I feel at home when I am around her. When I moved in with her, I used to get sick. She accompanied me to all medical appointments until I turned 18 years old. Even now she always calls to remind me to take my medicines and go for checkups." Male, 24 years.

However, other respondents had stressful family relationships including rejection and discrimination; lack of financial support; violence and abuse; property-related conflicts; and family members disclosing their HIV status to other people without their consent. Those respondents felt they had no one to turn to when in need:

"My mother died when I was young so my siblings and I were handed over to my aunt who does not treat us well. Life has been very hard for us. It is really hard and we struggle for everything including food, water and electricity and yet we have able relatives. It is a tough life that sometimes I just keep it to myself and take my medicines and hope that the future will be better for me and my siblings." Male, 22 years.

"*My family provides me with everything and I am happy with that. However, they should understand me instead of blaming me for the little things that I do. My sister says I am old enough to know why I should take my medicines well. I am living with people who do not know what I am going through. My mom is dead but I still feel it was unfair that she did this to me. Give me the virus. This feeling makes taking medicines everyday very tough for me. It is very tough but no one understands."* Female, 20 years

"I need support from my family before getting support from a psychologist. I think my family needs to be counselled and advised because I don't have the power to talk to them. Maybe they will listen to Baylor staff." Male, 19 years

Another family-related stressor reported by some respondents was not knowing or not having a close or supportive relationship with one's biological father. Respondents described fathers who they didn't know, lived elsewhere and who were "not supportive" either financially or emotionally. Having a paternal identity and a father figure or social support from the paternal family was a dominant motivation for the desire to know or have a close relationship with one's biological father.

"I don't know my father; my whole family doesn't want to tell me anything at the moment. I haven't asked a lot because they are not ready to tell me. As I grow older, I would want to know him and interact with him. I pray and I believe that one day he will turn up. I don't need anything from him, I just want to get to know him and know my other family." Female, 21 years

When asked to suggest ways to increase family support for YALPH, respondents proposed the following:

- Provide counselling to promote harmonious family relationships. Family members should be educated on the importance of maintaining confidentiality about the YALPH HIV status and providing financial support where needed.
- Provide training for YALPH on conflict resolution for them to manage the challenges they faced at home.

Relationships with Healthcare Workers:

Most of the respondents had been enrolled on ART at Botswana-Baylor since childhood. They referred to Botswana-Baylor as their "second home" and their HCWs as part of their extended families. Botswana-Baylor provided a supportive environment in which they felt safe and comfortable. All the respondents described the care they received from Botswana-Baylor as very good and some of the respondents relied heavily on their HCWs for general encouragement, instrumental support and adherence support. They described the ease with which they could communicate with the HCWs on various issues both clinical and psychosocial. The

patient-provider relationship was very helpful to those who were unable to rely on their caregivers and families for support. Some respondents were working in distant places but still travelled back for regular services at Botswana-Baylor.

Friendships and Peer Relationships:

Some respondents reported having affectionate and supportive friendships and peer relationships. In most cases, these were family members, school mates and peers whom they met at Teen Club and Young Adults Support Group meetings at Botswana-Baylor. Friends and peers were a source of emotional support and encouragement.

"I still haven't found a person I would call a best friend but some of my good friends we met at Baylor-Teen Club and Young Adults Support Group. Some of them are older than me. They help me out when I am in need because they understand my situation. When I tell them my problem they respond in a way I want them to respond, unlike someone who tries to understand but doesn't understand to a full extent." Male, 25 years

However, the majority of respondents both male and female reported difficulty with establishing or maintaining close friendships due to the fear of stigma and discrimination. The majority preferred to be alone or avoid visiting or going to social events and were friends with close family members only.

"I love being at home. Home is a very comfortable and safe space for me. I enjoy keeping to myself, reading books, and watching television. I would say my cousin is my best friend. We grew up together." Male, 18 years

Romantic Relationships:

Quantitative results from the WHOQOL-HIV BREF showed a low score for the item "Satisfaction with Sex Life" (56,92). In the in-depth interviews, respondents were asked how living with HIV affected their sex life.

The majority of the respondents had ever been in a romantic relationship (89%) and more than half (61%) were in a relationship at the time of the study. All respondents

perceived growing up with HIV infection to have negatively affected their ability to form and keep romantic relationships compared to their HIV negative peers.

"I am depressed all the time and on anti-depressants. The virus controls. It controls the time I have to be home, I can't drink alcohol like other youth, and I can't have sex when I need it. I feel totally out of control." Female, 21 years

Physical problems such as vaginal warts (2 female), erectile dysfunction (1 male) and heavy or irregular menstruation (2 females) were reported as issues affecting satisfaction with sexual life. Also, disappointments related to dishonesty, cheating, and physical and emotional abuse by partners were reported.

Respondents had multiple sources of information on sexual and reproductive health including schools, HCWs as part of clinical care, Teen Club, Young Adults Support Groups and the internet. The respondents reported that they had easy access to SRH services at the local clinics in their communities.

"During check-ups, the doctors and nurses make time for us to discuss these issues around sexual activity. It is great because I could not go to my aunt and be like I have started having this kind of feelings and I am not sure what they are. So it is nice to have someone you could run to and say this is what has been happening to me at the moment so what am I supposed to do, I am having feelings for this person, how do I go about it?" Female, 19 years

"The doctors told me about it a lot of times. They asked me who my girlfriend is. I felt funny because I told them the truth that I don't have a girlfriend. They will be like…in case you do it this is how you go about it…. I'm like okay. I know the risks. I think I am heavily educated because at school they talk about it a lot and Baylor staff remind me every time I come for check-up." Male, 18 years

Respondents were asked about their needs regarding the formation and management of sexual relationships. Their responses included the following:

- Botswana-Baylor patients should be encouraged to bring their partners for testing or counselling. Discordant couples should be counselled and helped to access pre-exposure prophylaxis (PrEP).

- Conduct camps for YALPH and provide education on how to adapt adult behavioural norms regarding sex and relationships such as being honest, not engaging in violent behaviour; and practicing safe sex all the time.
- Sexual and reproductive health (SRH) services including contraception, PMTCT, cervical cancer screening and PrEP should be accessed where the YALPH get other HIV related care because they lack the time to go to other health facilities. However, other respondents recommended that YALPH should be empowered to venture out and seek the services that they need.
- Those who had experienced sexual abuse or rape called for trauma counselling and prosecution of offenders.
- Caregivers and school personnel should be empowered to discuss topics on sexuality and relationships with YALPH more competently.

4.2.6.2 Stigma and Discrimination:

When asked to describe how living with HIV affected their QOL, fear, and worries about stigma and discrimination were spontaneously reported by the respondents. Respondents had constant fear and worry about how others would react upon knowing their HIV status. Some had the fear that some people were gossiping about them. As a result, the respondents felt the need to protect themselves by not disclosing their HIV status and or isolating themselves from social activities, friendships, and intimate relationships. For example, one respondent reported defaulting from treatment for 5 months due to fear of stigma:

"*When they see me going to the clinic regularly, I start imagining that they know or they may guess right. At one point I stopped coming for treatment for 5 months because there were too many people who knew me at Botswana-Baylor."* Female, 21 years

Some respondents had experienced stigma from a family member due to alcohol-related violence and or referring to their HIV status in family conflicts and quarrels. And 3 respondents had experienced stigma at school related to their medicines or regular clinic visits.

However, most respondents reported that they had fear of stigma but they had never experienced an act of stigma or discrimination because they were physically healthy and only close family members and a few trusted people knew about their HIV status. However, some respondents had heard negative comments or observed differential treatment of other PLWH.

"I have not experienced stigma or discrimination because they do not know. No one knows my status apart from my close relatives. I am healthy and I live like any other young person. But I am saddened by the things that students in my class say when discussing HIV/AIDS as part of Public Health Education sessions. The things they say are indicative that they are not accepting of HIV infected people." Female, 21 years

Respondents' suggestions on how to empower YALPH to manage HIV stigma in their environments included the following:

- Integrate HIV treatment and care services with other health care services so that people do not know others' HIV status by the services they line-up for.
- Encourage YALPH to participate in peer support groups such as Teen Clubs and Young Adult Support Groups. Support and advice from peers can help increase self-acceptance and decrease fear of stigma.
- Increase community education on HIV/AIDS targeting the youth because they are the ones they (respondents) interacted with mostly in schools, workplaces and the communities. Some respondents indicated the willingness to go public and use their personal experience with HIV to humanize the disease as well as increase prevention efforts among the youth.

4.2.6.3 Limited Financial Resources:

The quantitative results generated by the WHOQOL - HIV BREF showed that the lowest QOL scores were recorded in the Environmental domain of HRQOL. The low QOL scores in the Environmental domain were largely a function of limited financial resources.

In the in-depth interviews, respondents identified the lack of money to meet their basic needs as a major source of stress. Respondents spent a lot of time thinking of how to meet their financial needs. Financial problems were attributed mainly to unemployment, low and unreliable pay, orphan-hood, lack of capital and ideas to start businesses, disabilities and impairments. Some respondents lived in households with many family members who were not working, relied on the income of a few household members or government social welfare programs such as “Ipelegeng”, food basket and old people’s pension.

“The biggest challenge I would have to say is financial. I tend to spend most of my time thinking of how I can meet my budget. My parents passed away in 2010. Only one person is working in our family and the money he gets is not enough in a home of 6 people. My grandmother is not yet eligible for old people’s pension. Life is tough there is not enough to eat at home. When my aunts get piece jobs they contribute towards buying of food.” Female, 24 years

Respondents also reported that their families perceived them (young adults) as being old enough to be employed and to have financial independence. However, respondents did not yet feel like adults despite being of legal adult age since they lacked financial independence. They still needed financial and other support from their families and the Government of Botswana.

“There are too many conflicts in my family and they are all based on issues of money and spending and food. My mother says that I am now old enough to take care of myself and I should not be making demands like a child. She always wonders how I will manage when she dies. She wants me to go out there and be like other youth and supply myself with whatever I need. I need a job but I cannot find one." Male 23 years.

Financial problems negatively affected respondents' ability to meet transport costs to the clinic for medical appointments leading to occasional gaps in medication adherence. Lack of money was associated with limited access to leisure and entertainment leading to social isolation and loneliness. Respondents also reported limited access to the internet and other sources of essential information such as phones, television or newspapers due to lack of money. For young mothers and fathers, lack of money affected their ability to provide basic needs for their children. Financial difficulties also made it difficult for respondents to sponsor themselves to go back to school to re-sit examinations or enrol in vocational or tertiary level courses if they didn't qualify for government funding.

Lack of money led to food insecurity at individual and household levels. Going without food and poor nutrition was a frequent occurrence in some respondents' homes. The narratives showed that more than half of the respondents had ever benefited from the OVC food basket provided by the Government which was stopped when the beneficiaries turned 18 years old. In some cases, their household needs were assessed by the social workers but they didn't meet the criteria for continued Government assistance under the destitute support program. Food insecurity was also linked to intra-familial conflicts.

"My father and mother passed away many years ago. There is no one to buy me toiletry. My food basket was discontinued when I turned 18. My great grandmother is on old peoples' pension. My grandmother is on Ipelegeng jobs which are not regular. We also depend on my younger brother's food basket which will be discontinued next year when he turns 18 years. I have many uncles but they do not support us." Female, 19 years

The respondents proposed the following measures to help YALPH to deal with financial challenges:

- Help YALPH to access Government funded business capital and job opportunities to give them financial independence and ease their financial stressors.
- Review the Botswana Government policy on food support (food basket) and other OVC Support Programs. Food basket and other OVC support services for HIV infected youth should continue until a person completes school regardless of age or until they can work and feed themselves.
- Empower YALPH with skills in financial responsibility, which includes how to generate and save income.

4.3 CONCLUSION

The results from this study showed that most of the YALPH were clinically stable on ART; and they perceived themselves to be in good health and QOL. The highest HRQOL scores were observed in the Physical domain whereas the lowest scores were observed in the Environmental domain. Low HRQOL scores in the Environmental domain were largely a function of limited financial resources. The odds for having a good HRQOL were increased among YALPH with a high level of education and those who were employed. YALPH who had unsuppressed VL and those who were ill were at risk of poor HRQOL. Therefore, the promotion of the HRQOL of YALPH will require policies and interventions to increase educational attainment, provide employment and livelihood opportunities, promote good ART adherence and effectively prevent and manage illnesses. The YALPH had positive perspectives of the future including being in good health, completing school, finding productive employment, marriage and childbearing. However, some sub-groups of YALPH were at higher risk for poor HRQOL including young mothers and their children, YALPH who were aging out of institutional care, YALPH with disabilities and impairments, YALPH who were neither in school nor working, and YALPH with maladaptive coping strategies. Those sub-groups of YALPH will require special interventions to promote their HRQOL.

CHAPTER FIVE

DISCUSSION OF THE MAIN FINDINGS OF THE STUDY

5.1 INTRODUCTION

This chapter discusses the main findings of the study focusing mainly on the factors that were found to be strongly associated with HRQOL of YALPH in the quantitative and qualitative phases of the study. The structure of the discussion was based on the domains of the Ferrans Conceptual Model of HRQOL (Figure 2).

As mentioned earlier in the study, an increasing number of perinatally HIV infected adolescents are emerging into young adulthood throughout Botswana. However, one common theme in Botswana is the paucity of research in the area of YALPH including a lack of epidemiologic data to better define this population of youth on a national basis. There is also a general lack of information regarding the potential impacts of HIV on HRQOL in this population. This study, therefore, aimed to assess the HRQOL of YALPH, to identify factors that were associated with good or poor HRQOL and to propose policies to promote the HRQOL of those YALPH. The HRQOL of 509 YALPH was assessed using the WHOQOL-HIV BREF instrument, and the factors that were significantly associated with HRQOL were further explored through in-depth interviews.

5.2 GENERAL QUALITY OF LIFE OF THE SAMPLE (POOR OR GOOD):

The quantitative results generated by the WHOQOL-HIV BREF showed that the majority of YALPH (78.4%) had good general QOL. The high rate of perceived good QOL reported in this study may be attributed to many possible causes. All the respondents in this study were on ART. The positive effects of ART in PLWH include VL suppression, improved immune system, reduced AIDS-related illnesses, and improved HRQOL (Davey et al. 2018:6). This was supported by the qualitative results which showed that the majority of the respondents had very strong social and adherence support from their families, peer support groups and health care providers. The respondents also used a wide range of adaptive coping strategies to

live well with HIV. Additionally, the respondents in this study were enrolled on ART at Botswana-Baylor which is a Clinical Centre of Excellence and provides comprehensive high quality clinical and psycho-social services to patients.

5.3. GENERAL HEALTH PERCEPTIONS

The results of this study showed a strong relationship between illness perception and HRQOL. Respondents who reported that they were “currently ill” were associated with a reduction in the odds for good general QOL. Health is one of the most important factors contributing to HRQOL and the individual’s subjective assessment of their health is an important dimension of their general QOL (WHO 1946:100). The results imply that YALPH who experience illness or who perceive themselves to be ill are at high risk of impaired HRQOL. These results are in line with prior studies that showed illness in PLWH to be independently associated with HRQOL (George et al. 2016:5; and Mekuria 2015: 935).

Altogether, the majority of YALPH (86.5%) reported that their health was ‘good’ or ‘very good’. And the proportions of YALPH in the sample who regarded themselves as having an illness at the time of data collection were only 17.9%. In interpreting these results, it should be noted that YALPH who were very ill and those who did not have the physical or mental ability to participate were excluded from the study. As a result, this study did not assess the HRQOL of YALPH who had acute illness.

It is important to note that some respondents who did not have any diagnosed health conditions, perceived themselves as being ill due to their HIV infection. Some respondents reported illness-related worries and fears about medication side-effects, treatment failure, disease progression, and death. This, therefore, implies that prevalent negative illness cognitions or feelings of being unwell that are not consistent with diagnosed health conditions may contribute to poor HRQOL.

The findings of this study lead to the conclusion that the functioning and well-being of YALPH are inextricably linked to the illnesses they experience and targeting illnesses and illness cognitions may improve HRQOL. Therefore, interventions to promote HRQOL in YALPH need to focus on preventing and alleviating illnesses

such as symptoms of HIV/AIDS, co-infections, non-communicable diseases (NCDs), impairments, and other illnesses. Additionally, providing less toxic ART combinations must be a high priority for policymakers and health care professionals involved in treating YALPH. The YALPH need to be counselled and assessed to evaluate how satisfied they are with their health; and if they are not satisfied, they should be supported to come up with their own health goals and to set strategies on how to achieve them.

The Government of Botswana through the MOHW has a wide range of policies and programs that support the provision of high-quality treatment, care and support services to PLWH. As evidenced in this study, almost all respondents were on highly potent ART drug regimens that were taken once daily and were known to have few side effects.

The results of this study also highlight the need for interventions to promote the prevention and management of non-communicable diseases (NCDs) among YALPH. The literature review which was conducted as part of this study highlighted the growing evidence from other countries that the magnitude of NCDs risk factors was high among PLWH either due to the effects of HIV or prolonged use of ART (Biraguma, Mutimura & Frantz 2018:118). The Botswana HIV Clinical Care Guidelines require the identification and prompt treatment of illnesses such as cardiovascular and/or cerebrovascular diseases (MOHW 2016:18). However, to the researchers' knowledge, the magnitude and risk factors of NCDs among YALPH on ART in Botswana was not known.

The WHO has developed a global action plan for the prevention and control of NCDs (2013-2020) which provides global targets for the prevention and management of NCDs. The WHO guidelines call for the establishment and strengthening of national policies and plans and to promote research for the prevention and control of NCDs (WHO 2012: 2). Therefore, research studies are needed to inform policy, planning, and programming on prevention, control and management of NCDs among YALPH in Botswana.

5.4 BIOLOGICAL FUNCTION

5.4.1 Duration on ART:

This study assessed the HRQOL of YALPH who had been on ART for a long period (average 12.4 years). Contrary to expectation, the bivariate analysis showed a lack of a relationship between duration on treatment with HRQOL. These results are largely inconsistent with other studies that showed a decline or stagnation in mean subscale scores of QOL with increased duration on ART presumably based on the notion of treatment fatigue (Mûnene & Ekman 2014:7). These results were confirmed by YALPH in the in-depth interviews who perceived no problems with their treatment because they had been on it for many years. In addition, most of the respondents were on once-daily drug regimens which they described as being convenient with no side effects. The respondents were aware of the therapeutic benefits of good ART adherence and they were motivated to take their medicines well to remain healthy and fit enough to work, attend school, provide for their children and accomplish their future goals.

These results were also inconsistent with some studies that showed an increase in HRQOL with increased duration on treatment (Deribew, Deribe, Reda, Tesfaye, Hailmichael, Maja & Colebunders 2013: 5).

5.4.2 CD4 Cell Count:

Contrary to expectation, the results of this study showed that the level of CD4 cell count was not associated with the HRQOL. The findings are consistent with other studies that found weak or no correlations between CD4 cell count and HRQOL (Mafirakureva et al. 2016:911; Folasire, Folasire & Sanusi 2015:412; and Cronje, Williams, Steenkamp, Venter & Elkonin 2017: 632). The lack of association between CD4 cell count and HRQOL scores in this study was possibly because almost all respondents were asymptomatic with relatively high CD4 cell counts (mean=595 cells/mm3) and only 31 (6.09%) had CD4 cell count less than 200 cells/mm3. The results suggest that an increase or decrease in CD4 cell count may not translate to better or poorer HRQOL. This implies that clinicians and policymakers cannot rely on the change in immunological markers to predict HRQOL in the studied YALPH.

Therefore, in addition to monitoring immunological markers, other determinants of HRQOL need to be considered in promoting the HRQOL of YALPH. Similar studies in expanded samples with more diverse CD4 cell count scores would further enrich these findings.

5.4.3 Viral Load (VL):

Bivariate and multivariate analysis indicated a strong association between VL levels and HRQOL. The general HRQOL declined by almost two folds (OR = 0.59, 95% CI = (0.33 – 1.06)) amongst respondents with VL> 400 cell/mm2 compared to those with suppressed VL < 400 cells/mm2. VL levels are one of the indicators of disease progression in HIV/AIDS and therefore can potentially influence a person's self-perception of QOL. These results are consistent with other studies that showed that having a low VL positively impacts the HRQOL of PLWH (Bucciardini 2014:176; and Degroote et al. 2014:3). This association between VL and HRQOL indicators shows that these can be direct proxies of each other and that the VL alone may be adequate eligibility criteria for HRQOL interventions in YALPH.

The high VL suppression rate in this study (86.6%) was near the global UNAIDS '90-90-90' treatment target which promotes diagnosis of HIV, treating a greater number of those diagnosed and ensuring that 90% of those being treated achieve VL suppression. High VL suppression rates in a population imply reduced AIDS-related morbidity and mortality, good physical functioning, and are also important from a public health perspective since VL suppression would greatly reduce onward transmission of HIV to sexual partners and offspring (Davey et al. 2018:6).

Adequate attention needs to be paid to the 13.4 % of the YALPH who had unsuppressed VL not only for those individuals' health outcomes and QOL but also for control of the HIV epidemic among youth in Botswana. Low VL suppression rates have been identified in other perinatally HIV infected youths and have been found to increase as they approach young adulthood (Kahana, Fernandez, Wilson et al. 2015:169; and Xia, Shah, Gill, Torian & Braunstein 2016: 566). YALPH with unsuppressed VL are associated with drug-resistant virus, lower condom use and thus are at risk of transmission of HIV to sexual partners and their offspring

(Tassiopoulos, Moscicki, Mellins, et al. Paediatric HIV/AIDS Cohort Study 2013:289; Agwu, Bethel, Hightow-Weidman, et al; ATN 061 Team and the Adolescent Medicine Trials Network for HIV/AIDS Interventions 2012: 194).

Of concern in this study was the fact that almost all the respondents who had unsuppressed VL were on newer and highly potent drug regimens including integrase inhibitors that were given once daily and were known to have fewer/milder side effects. The lack of VL suppression among those YALPH was likely due to poor medication adherence because resistance to newer ARV drugs is uncommon (Van Dyke, Patel, Kagan, et al 2016: 133). In the in-depth interviews, the challenges with medication adherence reported by YALPH with unsuppressed VL included: fear of stigma, poor self-acceptance, side effects of ART, lack of medication adherence support from family members, and lack of transport money to go to the clinic for ART refill.

Some respondents with unsuppressed VL had been diagnosed with mental health problems which are known to affect ART adherence. Other studies conducted in Botswana also showed that depression and mental health were major problems contributing to poor ART adherence and poor health outcomes (Ndubuka et al. 2016:1; Ehlers & Tshisuyi 2015:7). A study by Ndubuka et al. (2016:1) in a population of adults in Southeast Botswana found that depression was one of the top three reasons why respondents missed ARV doses. Additionally, research from longitudinal cohort studies conducted in the USA suggests that YALPH are at high risk of mental health disorders including depressive disorders, anxiety disorders, substance use issues, post-traumatic stress disorders as well as psychiatric symptoms compared to their HIV negative peers (Abrams et al. 2018:1). Mental health disorders and psychiatric problems among YALPH have been associated with poor ART adherence, viremia, and poor health outcomes (Abrams et al. 2018:8 and Bucek et al. 2016:673). Therefore, screening, assessing, and treating specific categories of mental health and psychiatric problems may enhance efforts to improve adherence and prevent poor health in YALPH (Abrams et al. 2018:8 and Bucek et al. 2016:673).

Therefore, to promote VL suppression and HRQOL among YALPH, HIV/AIDS programs in Botswana need to identify, test, and scale-up high impact, young adult-friendly adherence support interventions. As had been demonstrated by other studies, adherence to ART influences one's HRQOL, and HRQOL influences one's ability or willingness to adhere to ART (Vagiri et al. 2018: 121). This bi-directional relationship between ART adherence and HRQOL highlights the need to enhance ART adherence to improve the HRQOL of YALPH.

Some youth-friendly intervention models to promote ART adherence and VL suppression which were proposed by YALPH in this study (peer support groups, residential camps, and phone-based support) need to be considered by policymakers and programmers. It is also imperative that the Botswana MOHW in collaboration with partners find ways to integrate mental health screening and management services into clinical care and other HIV programs targeting YALPH. This will require the development of guidelines and training for institutional and community-based service providers to timely identify, refer or manage mental health problems.

5.4.4 Body Mass Index (BMI):

This study found no association between BMI and QOL in contrast to previous reports that demonstrated a positive relationship between BMI and HRQOL (Tesfaye et al. 2016: 5; and Thapa et al. 2015:10). The results in this study could be attributed to response shift (Sprangers & Schwartz 1999:1510), implying that over time, YALPH had adapted to their weight and height and didn't have issues with it.

However, the high prevalence of low BMI in this population raises concern given that (39%) of respondents were underweight (BMI <18.5kg/m2) with 15.5% of the respondents being severely thin (BMI <17.0kg/m2). The low BMI was despite the fact that most of the respondents were on ART, had undetectable VL and good immunological status. These results confirm findings of other surveys in Botswana that found a high prevalence of low BMI (Letamo & Navaneetham 2014:5; and Botswana Demographic Survey 2017:58).

The high prevalence of underweight BMI in this population of YALPH may be attributed to many possible causes. Growth failure, including stunting, is one of the features of pediatric HIV infection and generally distinguishes youth with perinatally acquired HIV infection from their uninfected peers (Lowenthal et al. 2014: 6). Low BMI is also associated with low social-economic status and food insecurity (Tesfaye et al. 2016: 5; and Letamo & Navaneetham 2014:5). There is evidence that food insecurity and malnutrition are highly prevalent in Botswana due to various factors including inadequate food consumption, lack of food, lack of knowledge on food processing and preparation, poor dietary habits and poverty (Letamo & Navaneetham 2014: 5-6; and Mendoza, Matshaba, Makhanda, Liu, Boitshwarelo & Anabwani 2014:66).

The YALPH in this study reported food insecurity in their homes due to unemployment, poverty and large households with many unemployed people. Most of the respondents had benefited from the OVC food basket which was stopped when the beneficiaries turned 18 years old. In all cases, the withdrawal of the food basket exacerbated the food insecurity in respondents' households. The YALPH recommended the review of the Botswana Government's policy on "food basket" so that food support for vulnerable YALPH continues until individuals are able to work and feed themselves.

There are multiple programs aimed to provide food support to vulnerable populations in Botswana within the framework of the Revised National Food Strategy (2000:5) and the Essential Health Services Package for Botswana (2010:10). This is in addition to the ongoing social protection measures such as the universal school feeding program, OVC and Destitute Persons Support programs. However, the high prevalence of low BMI and food insecurity reported by this study suggests that more needs to be done in the area of food and nutrition support for vulnerable YALPH.

Two evaluations of the Botswana OVC Support Program which supplies the food basket (Feranil et al. 2010:38-39) and (MLGRD 2016:30-36) called for the setting up of well-funded and coordinated graduation efforts for OVC as they approach the age of 18 years. The recommendations included prioritizing caregivers of OVC and older OVC for income-generating programs.

There is also a need to involve multiple sectors including health, education, social protection, and other sectors to ensure that diverse nutritional support is provided from an early age to prevent malnutrition and preserve or establish normal weight in YALPH. As outlined in the Botswana Revised National HIV/AIDS Policy, health education regarding nutrition and nutritional values of foods particularly locally available foods should be provided to YALPH. However, caution should be taken to ensure that interventions aimed at weight gain for the underweight YALPH do not lead to overconsumption of fatty diets, uncontrolled weight gain, and increased risk for NCDs (Dimala, Atashili, Mbuagbaw, Wilfred & Monekosso 2016:2).

5.5 CHARACTERISTICS OF THE INDIVIDUAL

5.5.1 Level of Education:

In this study, the level of education attained (primary, secondary, or tertiary) was found to be significantly associated with general HRQOL. In the bivariate analysis, based on the p-values < 10%, the highest level of education attained was significantly associated with the general QOL (poor vs good). Respondents with low education levels (primary to senior secondary), had lower QOL scores in all domains of HRQOL, with the lowest score in the Social relationships domain.

Other studies also found that higher education promotes better HRQOL (Mutabazi-Mwesigire et al. 2015:7; and Tesfay et al. 2016:4). A tertiary or post-secondary education certificate provides some assurance of employability when jobs are available. In addition, people with higher education who are employed can afford a variety of foods needed to diversify diet and positively impact nutrition status (Thapa et al. 2015:10). Due to their educational qualification and professional status, people with higher level of education may have a better social support network of family and friends hence good QOL in the Social domain (Nglazi et al. 2014:8).

However, a large proportion of the YALPH in this study (40.3%) did not have a post-secondary or tertiary education qualification. Those respondents had failed their junior secondary or senior secondary school examinations and they did not qualify for government-sponsored post-secondary school training. In this study, poor school

performance and achievement were attributed to illness and hospitalization, illness-related fears and worries, visual and hearing impairments, and learning difficulties. Apart from limiting the prospects for employment, poor school performance and attainment heightened feelings of personal inadequacy and worthlessness and created fear and worries about the future.

These results are not surprising because, in perinatally HIV infected youth, schooling can be impacted by non-cognitive factors such as poor general health, low parental or caregiver educational attainment, but also due to HIV-related cognitive deficits. Perinatally HIV infected children and youth are at high risk for neurocognitive impairment in various areas such as executive functioning, language development, and memory, which potentially affect school performance (Abrams et al. 2018:8). Additionally, disabilities and impairments are common among HIV infected children and adolescents (Anabwani et al. 2016:8), increasing the risk for poor long-term academic and employment outcomes in young adulthood.

The YALPH in this study reported that identification and interventions for impairments and learning problems by schools were done too late to make an impact on their school achievement. There were also reports by some respondents that they were “slow learners” however they were not given the chance to learn slowly. The YALPH also reported that family members did not understand their school-related challenges did not provide them with academic support. These results call for further strengthening of the capacity of the education system to adopt early screening and diagnosis of cognitive problems, disabilities and impairments that may be amenable to remediation and other interventions. Paying attention to those deficits and impairments by the school system should serve as intervention targets for improving academic outcomes and HRQOL of YALPH.

The low educational attainment among the study population also reflects the limited ability of parents or families to support YALPH’s education-related goals. It is well known that HIV disproportionately affects people of low social-economic status (Pellowski, Kalichman, Matthews & Adler 2013:197; and Kalichman, Pellowski, Kalichman, Cherry, Detorio, Caliendo & Schinazi 2011:324). Families of low social-economic status are less likely to have the ability, financial resources or time

availability to monitor and provide children with academic support. Therefore, it is incumbent on schools in Botswana to intensify training sessions for parents and caregivers through the Parents and Teachers Association (PTA) on how to assist children and youth with perinatally acquired HIV in their school work. In addition, targeted counselling and career guidance and support should be integrated into all clinical and psycho-social support services targeting YALPH.

The perspectives of respondents regarding the support needed to improve educational attainment for YALPH included increased access to remediation and tutoring services for those with learning problems; increased access to vocational training opportunities for those who do not pass their secondary school exams; and the need for an alternative school system that is less academic and focused on vocational or practical skills development that also assures success in life for those who are not academically competent.

All the strategies which were recommended by the respondents to increase educational attainment were in line with the goals and provisions of the Revised National Policy on Education (Ministry of Education, 1994) and the Education and Training Sector Strategic Plan (ETSSP, 2015-2020). The Revised National Policy on Education (RNPE) provides for special education to vulnerable youths including those with special education needs, disabilities, and chronic illnesses such as HIV. The RNPE also provides for a mixed ability pre-service and in-service training for teachers to enable them to manage the wide range of learning abilities in schools. Besides, there are Guidance and Counselling (G&C) services in all primary and secondary schools to cater for the personal, social, health, academic, and vocational needs of learners.

Since 2015, the Government of Botswana has set a 5-year Education and Training Sector Strategic Plan (ETSSP: 2015-2020), to guide decision-makers and planners to reform and improve education after identifying several challenges within the education system. The plan intends to match qualifications and labour market requirements and to align education outputs with future employment needs. The ETSSP addresses issues of quality, relevance, access, equity and accountability across the entire sector, from pre-primary school to tertiary level (ETSSP, 2015-

2020). The ETSSP is hinged on the principles advanced by the RNPE, the "Education for All" movement, and the Sustainable Development Goal 4 which promotes quality and inclusiveness of education. As a result, several educational initiatives are in place to promote post-secondary school training for vulnerable youth. Examples of these initiatives include the Tertiary and Technical Education support program by the education sector to sponsor eligible OVC to tertiary and technical education.

Technical and Vocational Education and Training (TVET) in Botswana is delivered at different levels from certificate to diploma in different types of technical institutions and brigades. Historically, the brigades were established by communities to absorb children who would have failed to progress through secondary schools. Brigades are autonomous, community-based institutions that provide practical on the job training for Botswana youth. Training is offered in auto mechanics, agriculture, construction, office studies, carpentry, electrical, drafting, general maintenance, machinery, plumbing, tannery, textiles and welding. Additionally, OVC are assisted to access tertiary education through the OVC special dispensation on post-secondary education support.

HCWs and school personnel need to provide students in secondary schools with adequate information on tertiary and vocational training opportunities that are available to them. YALPH also need to be provided with adult mentors who can help them to navigate the complex systems and to access the available educational support programs. There is a need to replicate and scale-up these programs to increase access and utilization by the intended populations such as the large number of YALPH in this study who lacked post-secondary training.

However, there is limited research to support the current programs designed to assist vulnerable youth in accessing vocational and tertiary education in Botswana. Those programs need to be rigorously evaluated, to ensure that innovations detailed in policies and programs have been implemented as expected and implementation capacity gaps are identified and bridged. In line with the goals of this study, there is a need to assess the extent to which educational support programs have benefited specific populations such as YALPH. Such information would be important in

designing models and practices with strong evidence of efficacy in promoting HRQOL through post-secondary training completion.

5.5.2 Employment Status:

A significant relationship was found between being employed and the overall perception of HRQOL. Generally, increased odds for good general HRQOL was observed amongst individuals who were employed (OR = 1.61 (95% CI = (0.89 – 2.92) when compared to the unemployed group. Employment status had a significant relationship with the Psychological domain, Level of Independence and Spiritual/religion/personal belief domains of QOL. This finding is consistent with the results of other studies which showed a similar trend (Mafirakureva et al. 2016:904 and George et al. 2015:5). Employment provides resources that improve nutrition, buffer the effects of the stress of HIV infection, and thus serve to maintain good HRQOL (Mekuria et al. 2015:937). Additionally, employment constitutes a big part of the daily life of people and it can provide structure, a social support network, role identity and meaning which are key to young adults' development (Mekuria et al. 2015: 937). This shows the paramount importance paid work has on the HRQOL of YALPH, both as a source of income and social status.

In this study, YALPH who were employed reported a sense of self-worth and felt that life was meaningful. Employment was a motivation for medication adherence because health underlined the ability to be physically fit and to work. On the other hand, many respondents, particularly those who did not possess tertiary or vocational training qualifications were languishing in unreliable jobs, low paying, long working hours, heavy workloads, and sometimes in unhealthy and unsafe working environments. Those respondents moved from one low paying job to another and did not have prospects for career advancement. The heavy workload and long working hours were associated with a lack of time for other activities such as hobbies, social networking, or leisure and entertainment. The respondents wished to be supported to access vocational or tertiary level training to have the qualifications that they needed to find productive employment.

The most striking result was the high rate of unemployment in this population (47. 3%). Among YALPH in this study, physical health was not a barrier to employment

but rather the lack of academic qualifications, work experience and job scarcity. Other key barriers to employment included lack of capital & concepts to establish personal businesses. While some respondents were disadvantaged by their stature (low weight and height) because potential employers perceived them to be too weak for some manual jobs that they were applying for.

Unemployment was associated with financial vulnerability, a sense of worthlessness, and more pressure added on individuals who were already stretched by other stressors related to living with HIV. The YALPH did not feel like adults despite being of legal adult age because they lacked financial independence. For young mothers, unemployment made it difficult for them to meet the basic needs of their children.

Unemployment was also associated with idleness which often led to risky behaviors such as alcohol abuse. It is known that constructive engagement or constructive use of time such as employment, being a student or homemaking make up an important component of young adult functioning. The reduction in physical activity and social connections that come with employment might induce stress that compromises mental health. The relationship between unemployment and poor mental health is bi-directional. Youth unemployment is associated with poor mental health including stress and depression, and poor mental health could be a risk factor of unemployment (Strandh, Winefield, Nilsson, Hammarström 2014:440). Taking a life-course perspective, research suggests that unemployment during young adulthood, a very sensitive period, can independently affect health later in life (Fergusson, McLeod, Horwood 2014:735). The results of this study therefore showed that providing employment and financial independence among YALPH can be an effective strategy for promoting their mental health and HRQOL.

The goal of more and better jobs and reduced unemployment among the youth are major elements of the Botswana Revised National Youth Policy (MYSC, 2010: 6-8). The Revised National Youth Policy (RNYP) has a special dispensation for the economic empowerment of vulnerable youth living with HIV and other chronic illnesses. Within the framework of the RNYP, the Government of Botswana provides a wide array of policies and programs to raise the employment levels and economic self-sufficiency of youths. These programs include entrepreneurship funding

schemes, National Service Program (Tirelo Sechaba), National Internship Program, Public Works Program (Ipelegeng Program) and up-skilling through expanded access to tertiary and vocational training.

Those policies and programs are deployed to further the employment and livelihood prospects among all unemployed youth. However, there are currently no large-scale approaches with the demonstrated capacity to improve the employment and livelihood outcomes of young people living with HIV in Botswana. The results of this study which showed a high unemployment highlighted the need for schools, HCWs, social workers and other service providers to provide YALPH with up-to-date labour market and youth development funding information. Additionally, organizations that serve youth living with HIV such as the Botswana-Baylor need to be engaged in policy and programmatic dialogues such as in the design and evaluation of employment and entrepreneurial schemes to ensure that the needs of YALPH are catered for. To meet the unique needs of YALPH will also require a heightened public understanding of the challenges they face and robust public and private investment in their job training and opportunities for employment.

In terms of intervention, YALPH can receive assistance through addressing the barriers that hold them back when seeking employment including increasing access to technical and vocational education training, more opportunities for internship and apprenticeship, and on-the-job training opportunities as a pathway from unskilled to skilled jobs. HIV programs must continue to focus on the immediate health needs of YALPH while incorporating a livelihoods approach into their programs.

5.6 CONCLUSION

The study results have highlighted the determinants of good HRQOL in YALPH and what needs to be done to help more YALPH to make a successful transition to adulthood and to promote their HRQOL. Policy efforts and interventions to promote the HRQOL of YALPH need to focus on developing and scaling-up high impact, young adult-friendly adherence support interventions. The results indicate the need to address environmental and individual factors that affect adherence and viral suppression. Patients' self-appraisal of their health significantly determined their QOL, with lower QOL recorded among those who perceived themselves as ill. Therefore, alleviating symptoms of HIV, preventing co-morbid conditions, preventing and managing NCDs and metabolic complications of ART is important in improving the HRQOL of YALPH. Additionally, providing comprehensive and consistent counselling and education for YALPH on their disease state is recommended. Additionally, providing vulnerable YALPH with support to access tertiary and vocational training opportunities; and providing access to employment and livelihood opportunities are key to promoting their HRQOL. A multi-disciplinary and multi-sectoral approach will be needed to address the barriers that hold YALPH back and to promote their HRQOL.

CHAPTER SIX

PROPOSED POLICY GUIDELINES TO PROMOTE THE HRQOL OF YALPH IN BOTSWANA

6.1. Introduction and Background:

The primary purpose of this study was to propose policy guidelines to promote the HRQOL of YALPH in Botswana. According to WHO, data from HRQOL assessments can be used to inform and mobilize support for health policies and legislation, guide needs-based allocation of resources and monitor the effectiveness of interventions and programs at all levels hence incorporating the service recipient's voice into health care decision making (WHOQOL Group 1998:4). Accordingly, these policy guidelines were developed based on the findings from this study on the HRQOL of YALPH in Botswana.

The results of this research showed that the majority of YALPH enrolled on ART at Botswana-Baylor were clinically stable and their health outcomes of VL, CD4 cell count and health perspectives were good. The results also showed that the predictors for good HRQOL in the studied YALPH included individual characteristics (lower education level, unemployment), biological endpoints (unsuppressed VL) and functional status (being ill). The qualitative results from in-depth interviews showed that the predictors of poor HRQOL among YALPH were potentially modifiable risk factors that could be effectively targeted for policy action and intervention. Therefore, these policy guidelines aim to increase awareness of the unique needs of YALPH and guide interventions to promote their HRQOL.

6.2 Objectives of the Policy Guidelines:

The objectives of these policy guidelines are as follows:

- To propose advocacy, awareness, and mobilization activities and strengthened individual, family, community, and sectoral responses to the HRQOL of YALPH that are needs-driven and mainstreamed into broader HIV/AIDS and youth development programs in Botswana.
- To promote higher educational attainment as a means of increasing employability, financial independence and the HRQOL of YALPH.

6.3 Context of the Policy Guidelines:

The policy guidelines to promote the HRQOL of YALPH will operate in an environment that has many other existing policies and programs that aim to promote the health and wellbeing of youth and PLWH in Botswana. The policy guidelines will ensure that services provided to YALPH are developmentally appropriate and need-driven recognizing the fact that while general youth or PLWH services may be appropriate, modifications to existing services or entirely new approaches may be needed to promote the HRQOL of YALPH.

The key policies and programs that inform these guidelines include the following (the list is not exhaustive):

- The Revised National Health Policy (Ministry of Health 2011:1-41) and the Essential Health Service Package (EHSP) for Botswana (Ministry of Health 2010:1-142). Within the framework of these policies, the Government of Botswana provides a primary health care system that offers essential health services in an evenly accessible way to all Batswana. All YALPH have access to free health care services through the public health care system.

- The Revised National Policy on HIV/AIDS (National AIDS Coordinating Agency 2012:1-19) whose objectives include preventing the spread of HIV infection and reducing the socio-economic impact of the disease; creation of a policy environment for the provision of adequate and equitable care and support to those infected and affected with HIV and AIDS; and reducing stigma and discrimination towards PLWH in society. As part of this policy, YALPH have access to free ART treatment, care and support services provided by the MOHW and other partners under the “Treat all policy”. The Government of Botswana through the MOHW provides high-quality treatment, care, and support services to PLWH. As evidenced in this study, the majority of respondents were stable on highly potent ART drug regimens including integrase inhibitors that were given once daily and were known to have fewer/milder side effects. Also, the highest HRQOL score was observed in the Physical domain denoting good health among the studied population.
- National HIV/AIDS Strategic Framework III (National AIDS Coordinating Agency 2018: 7). The main goals of the NSF III include preventing new HIV infections; and scaling up treatment, care and support services for HIV infected people (NACA 2018:8). The NSF III is anchored in the Eleventh National Development Plan (2017-2023) whose goals include improving access to quality health care services, preventing HIV infections and working towards ending HIV/AIDS as a public health threat by 2030 (Ministry of Finance and Development Planning 2017:190).
- Within the framework of the Revised National Policy on Education (RNPE) (Republic of Botswana 1994:7), and the Education and Training Sector Strategic Plan (2015-2020), the Ministry of Basic Education and the Ministry of Tertiary Education, Research, Science and Technology promote an inclusive education system and provision of special education to vulnerable youths including those with special education needs, disabilities and chronic illnesses such as HIV. Besides, the Government of Botswana through the Tertiary and Technical Education Support Program sponsors eligible OVC to tertiary and technical education. The project has a special dispensation for unemployed youth and those with special educational needs. Therefore, this

policy is highly relevant to YALPH given the finding that many of them lacked post-secondary education qualifications because they had failed their secondary school examinations which they attributed to a range of disabilities, impairments and learning problems.

- Youth development in Botswana is undertaken within the framework of the the Revised National Youth Policy (RNYP) of 2010 (MYSC 2010). The RNYP has a special dispensation for the economic empowerment of vulnerable youth including the development of programs and projects for young people living with HIV and AIDS. The key programs provided within the framework of this policy include: 1) youth business financing schemes which are funded by the Government of Botswana to address the issue of unemployment through the development of sustainable business projects; 2) the Botswana National Service Program (BNSP) or Tirelo Sechaba and National Internship Program introduced to allow the youth to acquire work skills and experience and increase their chances of gaining employment in the future; and the Botswana Public Works Program aimed at short term employment support and relief. The provisions of this policy are highly relevant to YALPH given the high prevalence of unemployment and lack of financial independence reported in the studied population.

Other policies and guidelines that are relevant to YALPH include:

- Adolescent and Young People HIV/AIDS Framework 2018-2022 (NACA 2018)
- Handbook of the Botswana 2016 Integrated HIV Clinical Care Guidelines (MOH 2016).
- Vision 2036

6.4 Policy Gaps:

The following identified gaps need to be targeted for policy action to promote the HRQOL of YALPH:

- Lack of surveillance data on YALPH. The lack of surveillance and other information on YALPH can compromise planning, budgeting and service delivery for them.
- Many YALPH lacked post-secondary school training and many were unemployed providing evidence that various educational and employment support programs provided by the Government of Botswana and other partners were not being fully utilised by some YALPH for a host of reasons (including lack of information, lack of confidence to apply, or long/complex application processes). Therefore, efforts should be made to empower the YALPH to access and utilize those services to promote their HRQOL.
- Inadequate involvement of YALPH in the development, implementation and evaluation of interventions intended to benefit them.

6.5 Focus and Guiding Principles of the proposed Policy Guidelines:

These policy guidelines will focus mainly on the following areas:

- The guidelines have a focus on the policy level, as opposed to the program or intervention level.
- The policy guidelines are focused on young adults living with HIV who are aged 18-30 years with a special focus on YALPH.
- The policy guidelines are focused on promoting YALPH as a unique population in policy and programming and will have a major focus on increasing educational attainment among YALPH.

In addition, the policy guidelines are founded on the following principles:

- Aligning the interventions to promote the HRQOL of YALPH with the developmental tasks of young adulthood.
- The rights-based approach to programming for YALPH.
- Mainstreaming and integrating care for YALPH into already existing health, education and youth development programs.
- Strengthening partnerships at all levels and building coalitions among key stakeholders.
- Enhancing the capacity of families and communities to respond to the needs of YALPH.
- Strengthening the capacity of health and educational institutions to serve YALPH.
- Additional focus on the highly vulnerable groups of YALPH who are at high risk of poor HRQOL including young parents, those who are aging out of institutional care, and YALPH who are out of school and not working.
- Using a participatory approach by involving YALPH in policy and program development, implementation and evaluation.

6.6 PROPOSED POLICY OPTIONS:

6.6.1 Policy Option 1 – Advocate and mobilize for increased multi-sectoral efforts to promote the HRQOL of YALPH:

A coordinated effort by the Ministry of Health and Wellness (MOHW), the Ministry of Basic Education (MOBE), and other partners is needed to address the unique needs of a growing population of YALPH in Botswana. To meet the unique needs of YALPH will require concerted efforts to develop and operationalize interventions that specifically promote their health, educational attainment, employability and HRQOL.

Policy actions:

- Develop national-level HIV/AIDS strategies that include an explicit focus on young adults living with HIV. All government and non-governmental organizations that fund programs or provide services to PLWH or research affecting PLWH should whenever possible distinguish young adults from adolescents and older adults. This will include providing disaggregated data on young adults by age and gender and reflect the situation of young adults living in different circumstances and of young adults in need of special support. Such data should be used to inform national policy and programming for YALPH.
- The MOHW and other program funders should ensure that the recognition of young adults as a unique population is reflected in operational budgets and that the costs of implementing strategies and interventions are not simply subsumed under budget lines for adolescents or all adult's HIV/AIDS treatment and care.
- Key to advocacy efforts should be the involvement and participation of institutions that serve YALPH such as the Botswana-Baylor or engaging YALPH themselves in the development and implementation of policies and programs that affect them. For example, YALPH who grew-up in institutional care and those who benefited from other OVC support programs should be consulted in the development of OVC and other social welfare programs; young parents should participate in the development of maternal-child care programs; YALPH with disabilities and impairments should be involved in special education or disability programming or policy development, and those who are neither in school nor working should participate in livelihood programming.
- The MOHW should create a multi-sectoral task force to address the needs of YALPH including health, education, social welfare, youth development, Community Based Organisations (CBOs) and Non-Government Organisations, YALPH, United Nations agencies (UNICEF, UNFPA, UNAIDS and UNDP), and other relevant institutions that serve YALPH. The structure

should have both national and district representation. Additionally, the structure should have an official mandate and reporting mechanisms. Those partner institutions that serve YALPH should collaborate to develop evidence-based and impactful models for promoting the HRQOL of YALPH. This should include the allocation of resources to expand implementation research on YALPH.

- Relevant government policies and programs should be evaluated to assess the extent to which they serve YALPH. Therefore, the creation of new policies and programs should first attempt to modify existing efforts to better suit the YALPH.
- Policymakers and program developers should seek opportunities for efficient delivery of services to YALPH through integration into already existing programs and services at institutional and community levels. For example, essential services such as mental health screening for YALPH should be integrated into routine HIV/AIDS clinical care; screening for neuro-cognitive impairments should be integrated into school health services delivery, Guidance and Counselling Program or Special Education Program; YALPH friendly ART adherence support should be integrated into clinical care or community-based Young Adults Support Group activities.
- The MOHW should allocate financial resources to build the capacity and train HCWs, teachers, social workers and other service providers to develop the skills and knowledge needed to address the needs of YALPH. The minimum package for training and capacity building should include service delivery guidelines and tools, descriptions of evidence-based and developmentally appropriate care models for YALPH; and guidelines for monitoring and evaluation of interventions. Where possible, the training should be integrated into already existing pre-service and in-service training courses for key service providers.

- The MOHW should create an inventory of services that target YALPH including programs, service coverage, and alternative approaches to responding to the needs of YALPH.
- The MOHW and the MOBE should collaboratively propose recommendations towards the development of a national program on YALPH; and propose a system, including indicators that will monitor and evaluate the effects of the proposed interventions.

6.6.2 Policy Option 2 - Increase the educational attainment of YALPH as a pathway to employment and better HRQOL:

The results of this study showed that a higher level of education and being employed are predictors of good HRQOL in YALPH. Additionally, it is well known that education, employment and financial resources are closely interrelated and they positively impact the HRQOL of individuals. However, the very weak education, employment, and livelihood outcomes of YALPH in this study raise particular concern. Many YALPH had failed their secondary school examinations and did not progress to vocational training or tertiary education. As a result, many of those YALPH were neither in school nor working.

Poor educational attainment among the YALPH was attributed to illness and hospitalization, visual and hearing impairments, learning difficulties, illness-related worries and anxieties, HIV related stigma in schools, and some YALPH did not expect to survive to adulthood and therefore did not study hard. Perinatally HIV infected children and youth are also known to be at high risk for neurocognitive deficits in various areas such as executive functioning, language development, and memory, which potentially affect school performance (Abrams et al. 2018:8; Garvie et al. 2014: 232; Sirois et al. 2016: 24; and Ene et al. 2014: 496). Additionally, visual and hearing impairments are common among HIV-infected children, adolescents and young adults, increasing the risk for poor academic outcomes (Anabwani et al. 2016:8).

Within the framework of the Revised National Policy on Education (1994) and the Training Sector Strategic Plan (2015-2020), the Ministry of Basic Education and the Ministry of Tertiary Education, Research, Science and Technology have a series of programs that support the academic performance and achievement of YALPH within the school environment. These include the Special Education Program for learners with special education needs and disabilities; the School Guidance and Counselling (G&C) Program that caters for the personal, social, health, academic, and vocational needs of learners; and the Tertiary and Technical Education Support Program that sponsor eligible OVC to tertiary and technical education. However, the high numbers of YALPH who did not have post-secondary qualifications showed that more needs to be done to support the educational attainment of YALPH and promote their HRQOL.

Therefore, these policy guidelines aim to address a range of barriers to educational attainment, increase success rates in secondary schools, increase the number of YALPH who join and complete post-secondary training and ultimately increase their employability, livelihood and HRQOL.

Policy Actions:

- The Ministry of Basic Education (MOBE), regional education offices, and schools should rigorously evaluate, enhance and or scale-up programs to create a favourable school environment for learners with HIV. This should include provision of nutritious meals as part of the school feeding program, and counselling services to promote adaptive coping among YALPH.
- The MOBE should also provide technical and financial supports for the education system to identify, adopt and scale-up additional models that have already been evaluated and generated positive impacts on academic success rates for chronically ill learners including those who are living with perinatally acquired HIV.
- The MOBE should collaborate with MOHW to identify, test and validate simple in-school neuro-cognitive screening tools. Additionally, the MOBE and MOHW should collaboratively develop or adopt, implement, and evaluate

neuro-cognitive remediation and intervention programs. The school Guidance and Counselling Program, the Special Education Program, and or school clinics should conduct routine neuro-cognitive screening for all learners with special needs, identify those who have cognitive deficits, and refer them for early remediation and other interventions. The MOBE should provide technical assistance for any schools that undertake routine cognitive screening by providing screening tools and staff training and also should rigorously evaluate the screening programs to assess their effectiveness.

- The MOBE in collaboration with MOHW should strengthen the capacity of the school health system to screen and identify learners with presumptive mental health issues and refer them for medical support. The MOHW should provide technical assistance to any schools or educational institutions that undertake routine mental health screening and referral by providing screening tools, training, and assistance, and should rigorously evaluate the school-based mental health screening program.
- To improve the education outcomes of YALPH will require improving both the information available to learners and teachers in schools about available services particularly about tertiary and technical education. MOBE should fast track access to educational support services by YALPH. The MOBE should establish structures and mechanisms to ensure that such educational supports are accessed by the learners with HIV and they indeed benefit their academic achievement.
- Learners must also be provided with labour market information so they can make better-informed choices regarding where and what to study. Learners with HIV also need career counselling from teachers who are well-informed about their strengths, weaknesses, and needs. Targeted counselling and career guidance and support should be integrated into all psycho-social support and clinical services targeting YALPH in schools, health facilities, and community-based programs such as peer support groups.
- YALPH who are out of school and their service providers should be informed about educational support programs that are available to them and provide adult mentors to guide them to access those services.

- The Government of Botswana should increase preferential access to vocational training opportunities for vulnerable youth who failed their secondary school examinations to equip them with job skills and increase their employability. Preferential offers should be considered for young parents and youth who are transitioning from institutional care back to their homes or to independent living in the community.
- The education system should consider the establishment of an alternative school system that is less academic and focused on vocational or practical skills development that also assures success in life for learners who are not academically competent.

6.7 CONCLUSION

There are many opportunities to advance the HRQOL of YALPH through the policy guidelines described above. However, sufficient efforts should be made to operationalize those guidelines. If these policy guidelines to promote the HRQOL of YALPH have to be operationalized, the MOHW and the MOBE should continuously identify and address barriers to action. The MOHW and MOBE should also continuously build capacity at all levels, including at institutional and community levels through training and provision of technical support and allocation of resources to enable relevant partners to plan, implement and evaluate interventions to promote the HRQOL of YALPH.

CHAPTER SEVEN

RECOMMENDATIONS AND GENERAL CONCLUSIONS

7.1 Introduction:

This chapter presents the researcher's general conclusions and recommendations for the way forward based on the results of the study. The purpose of the study was to identify the factors that were associated with HRQOL in YALPH and to propose policy guidelines to promote their HRQOL. Previous chapters (4-6) have fulfilled this task by identifying the determinants of HRQOL in YALPH and proposing policy guidelines to promote the HRQOL of YALPH in Botswana.

7.2 Recommendations:

The researcher provides the following recommendations founded on the results of the study:

- Differentiate young adults from other PLWH in policy and programming. Due to the unique challenges and support needs identified by this study, YALPH should be viewed as a distinct subpopulation in health policy, programming and research. National level surveillance data focusing specifically on this population should be provided to guide policy formulation and programming.
- The MOHW should intensify the mobilization, advocacy and action to promote the HRQOL of YALPH. The MOHW as the custodian of health services and policy in Botswana ought to lead the initiative to promote the HRQOL of YALPH. This can be done by raising awareness among policymakers, programmers, health managers, clinicians and other service providers. Training on the effects of HIV on the developmental tasks of young adulthood and evidence-based models to promote the HRQOL of YALPH should be conducted for health care professionals, social workers, teachers and other

service providers. The MOHW should provide technical support to ensure that partners develop, implement and evaluate impactful interventions to promote the HRQOL of YALPH.

- The findings of this study support the incorporation of HRQOL assessment into all treatment, care and support programs that serve YALPH in Botswana. Healthcare providers and policymakers need to plan and implement programs to routinely assess the HRQOL as an outcome measure of ART treatment and care.
- It is also imperative that the MOHW in collaboration with partners find ways to integrate mental health screening and management into clinical care and other services targeting YALPH. Some YALPH in this study reported being diagnosed with mental health problems for which they were seeing a psychologist or were on treatment. Mental health disorders and psychiatric problems among YALPH have been associated with poor ART adherence, viremia and poor health outcomes (Abrams et al. 2018:8; and Bucek et al. 2016:673). Therefore, screening, assessing and treating specific categories of mental health and psychiatric problems may enhance efforts to improve ART adherence, prevent poor health and promote HRQOL in YALPH. This will require the development of guidelines and training for service providers to timely identify, refer or manage mental health problems in YALPH.
- The Ministry of Basic Education should conduct routine neuro-cognitive assessment, remediation and other interventions in schools with a special attention to children, adolescents and young adults with perinatally acquired HIV. The results of this study showed that higher educational attainment was associated with better HRQOL in YALPH. However, many YALPH lacked post-secondary education and training. The literature review which was conducted as part of this study showed that that perinatally HIV infected youth are at high risk for neurocognitive deficits (Abrams et al. 2018:4). In the presence of neurocognitive deficits and other impairments, the potential for educational excellence is compromised. Therefore, within the framework of the Special Education Program in schools, a simple score for neuro-cognitive assessment should be developed or adopted and routinely used to identify

children and youths with neurocognitive deficits and refer them for remediation and or other interventions. However, once the interventions with positive outcomes have been identified, they will need to be scaled up and their effectiveness evaluated through implementation research.

- All service providers caring for YALPH should pay greater attention to the Environment domain of HRQOL that showed the lowest mean scores in this study. The low mean scores of HRQOL in the Environment domain were largely a function of limited financial resources. This implies that additional effort is needed to tackle unemployment and to increase financial resources through more livelihood opportunities. Within the framework of the RNYP, the Government of Botswana provides a wide array of policies and programs to raise the employment levels and economic self-sufficiency of youths. The results of this study which showed a high unemployment rate among YALPH, justify the need for service providers to come up with comprehensive interventions to support YALPH to access those programs and services in order to promote their HRQOL.
- The results of this study showed that the situation of YALPH women who were parenting was challenging. Most young mothers were single parents, they lacked post-secondary education qualifications, and they had financial stressors due to unemployment. Therefore, the promotion of the HRQOL of YALPH parents should be prioritized and should be based on the two-generation model of programming that invest simultaneously in mothers and their young children. Such interventions should aim to support young mothers in fulfilling their parenting responsibilities but also help them to access health, education and employment opportunities.

7.3 Limitations of the Study:

This study had several limitations that future research should endeavour to address.

First of all, causality could not be proven because of the cross-sectional nature of the study. Secondly, the entire study sample was selected from Botswana-Baylor which is a Clinical Centre of Excellence with the majority of patients being clinically stable on ART. It should be noted that the study sample did not include young adults who were not on ART, sick or hospitalized, and those who were behaviourally infected. The Botswana-Baylor is a large facility and serves youth from a wide geographic area representing both urban and rural living environments. However, despite this apparent representativeness, ART sites in Botswana vary greatly in the clinical composition of their patients.

And lastly, the respondents reported that the WHOQOL-HIV BREF instrument lacked “why” questions that would have allowed them to provide narratives to justify their scores on the Likert scale. Respondents also commented that the instrument lacked questions that would directly assess issues that affected their wellbeing prominently such as stigma and discrimination, food insecurity, unemployment and challenges with disclosure of HIV status to other people. For this study, some of those issues were explored in the in-depth interviews.

Hence those limitations should be considered in applying the findings of this study to other settings and populations.

7.4 Contributions of the study:

Despite the limitations of the study mentioned in section 7.3, the researcher is confident that the study results will contribute to the body of knowledge on the health and wellbeing of YALPH in Botswana. This study is the first to examine the HRQOL among YALPH in Botswana and it highlights the need for future studies to further direct evidence-based action towards improving the HRQOL in this population. The

study advances current research on HRQOL by presenting the social-demographic and clinical characteristics of a large representative sample of YALPH enrolled at a single ART site.

Additionally, the study provides descriptive data on the determinants of HRQOL of YALPH, an emerging population that is not well represented in explorations of HRQOL among PLWH in Botswana. The perspectives of YALPH on how their HRQOL could be promoted are provided. Therefore, this study can be considered as a reference point for future research and programming on the HRQOL in YALPH in Botswana. It is an advantage for both clinicians and programmers to have a better understanding of factors that may improve the HRQOL of YALPH. A precursor to improving the HRQOL of YALPH is knowledge of the factors that influence it, upon which appropriate interventions could be developed.

7.5 Future Research:

The results of this study identify a need to enhance existing surveys or research focused on either adolescents or adults to advance knowledge regarding the HRQOL of YALPH. Given that the HRQOL of YALPH encompasses a wide range of issues as identified by this study (health, education, employment, social welfare and others), different disciplines and sectors will have to collaborate to ensure that the various domains and facets of HRQOL are integrated into research designed to promote the HRQOL of YALPH. It would be important for the MOHW, donors, research institutions, and institutions that serve YALPH to identify research priorities and integrate them into the national research agenda. As a starting point, the following areas are priorities for future research to promote the HRQOL of YALPH:

- The results of this study showed a strong relationship between suppressed VL and good HRQOL. Therefore, there is a need for research to identify the factors that contribute to and enhance ART adherence and VL suppression in YALPH in Botswana. Perfect adherence to ART is needed to achieve VL suppression which in turn improves the HRQOL of YALPH and reduce further

transmission of HIV. The VL suppression rate of 87.4% found in this study was encouraging; however, achieving perfect adherence and VL suppression for all the YALPH on ART should be the target. Therefore, data generated from intervention studies is needed to show what works best to promote long-term ART adherence in YALPH in Botswana. For instance, there is a need to explore how information technology and social media can be used to influence ART adherence in YALPH.

- The results of this study showed that YALPH who experience illness or who perceive themselves to be ill are at high risk of impaired HRQOL. The majority of respondents in the study were clinically stable on highly potent ART drug regimens. However, there is growing evidence in the literature that perinatally infected youth are at high risk for non-communicable diseases (NCDs) and other metabolic complications related to ART and HIV (Dapena et al. 2012: 529; Blázquez, et al. 2015:6; and Vigano et al. 2010: 431). Those studies recommend the development of effective strategies to monitor, prevent, and manage NCDs and metabolic complications of ART. To the researcher's knowledge, there was paucity of research on the prevalence and risk factors for NCDs among YALPH in Botswana. Hence studies should be conducted to better understand how NCDs and metabolic complications of ART affect the YALPH in Botswana and how they can be prevented, controlled and or managed.
- This study showed that 47.3 % of respondents were neither in school nor working. Those YALPH had failed their secondary school-leaving exams and were not able to progress to post-secondary or tertiary level education. This highlights the need for research to understand what works best to support YALPH who are neither in school nor working to transition to higher education and the labour market.
- The study findings showed that some of the YALPH used maladaptive coping strategies including venting, denial, substance use, self-distraction and self-blame to manage the stress of living with HIV, hence putting themselves at high risk for poor HRQOL. There is a need for research on how YALPH may benefit from interventions promoting adaptive coping responses to HIV-

specific stressors. This calls for research to understand what works to support and transition YALPH from maladaptive to adaptive coping.

- The results of this study showed that some YALPH were transitioning from institutional care where they grew up back into their families of origin or independent living in the community. However, there was a lack of information on the YALPH regarding their wellbeing after transitioning from institutional care. There is a need for research to gain more knowledge on how YALPH who exit from institutional care fare during young adulthood and over time, providing a detailed longitudinal perspective on their HRQOL.

  Additionally, there is a need for research to identify effective practices for assisting YALPH in transitioning from institutional care. In conducting those researches, researchers and programmers familiar with the YALPH in institutional care as well as representatives of YALPH should be involved. Doing so would help ensure that study designs, including sampling and recruitment strategies and survey items, will better capture the experiences of YALPH.
- Lastly, the present study focused on the HRQOL of YALPH. Future research should explore the determinants of HRQOL of young adults who acquired HIV through sexual contact or other means. By comparing the determinants of HRQOL in the two groups of young adults, policymakers and programmers will be able to identify areas of interface and joint action while remaining sensitive to differences across the two subpopulations.

7.6 GENERAL CONCLUSIONS

The results of this study showed that the majority of YALPH enrolled on ART at Botswana-Baylor were clinically stable on ART and perceived themselves as having good HRQOL. Despite the challenges of living with perinatally acquired HIV and facing complex psycho-social challenges, many YALPH were achieving normal adult milestones of completing school, finding employment, engaging in romantic relationships and parenting. The health outcomes of VL, CD4 cell count and health perspectives of YALPH were good. However, large numbers of YALPH had underweight BMI and some had unsuppressed VL warranting strong nutritional and ART adherence interventions in this population.

The results of the study demonstrate that being on ART alone does not guarantee HRQOL for YALPH. Many other individual characteristics (education level, employment status), biological endpoints (VL suppression), and functional status (illness experience and perspectives) are responsible for changes in HRQOL. With appropriate prevention, treatment and management of HIV symptoms, medication side effects and illnesses, clinicians and other providers can help improve the HRQOL of YALPH. Through modification of individual ART adherence behaviours, with support from families, clinicians and peers, YALPH can attain VL suppression and enhance their HRQOL. In addition, policies and interventions to empower YALPH to access post-secondary education training and to find employment and livelihood opportunities are needed to promote their HRQOL. Extra attention should be paid to

The use of the Ferrans Conceptual Model of HRQOL was supported in this study as a good guide to HRQOL research. Therefore, it can be concluded that the Ferrans Conceptual Model of HRQOL can be used to guide the design, implementation and evaluation of multi-domain interventions to promote the HRQOL of YALPH.

LIST OF REFERENCES:

Abrams, E. J., Mellins, C. A., Bucek, A., Dolezal, C., Raymond, J., Wiznia, A., Jurgrau, A., Bamji, M., ShiunLeu, C., Warren, Y. (2018). Behavioral Health and Adult Milestones in Young Adults with Perinatal HIV Infection or Exposure Pediatrics. *J AdolescHealth*, 63(2), 157-165. Doi: 10.1016/j.jadohealth. 2018.02.004.

Aldaz, P., Moreno-Iribas, C., Egüés, N. *et al.* Mortality by causes in HIV-infected adults: comparison with the general population. *BMC Public Health 11*, 300. (2011). https://doi.org/10.1186/1471-2458-11-300

Allsop, J., Ashby, J., Fidler, S., Foster, C., Garvey, L., Paramesparan, Y., Taylor-Robinson, S.D., Wan, T., Winston, A. 2015.Cerebral function in perinatally HIV-infected young adults and their HIV-uninfected sibling controls. Journal: HIV Clinical Trials. Volume & Issue: 16 &2. 81-7. DOI: 10.1179/1528433614Z.0000000003

Amgalan. N., Shin. J. S., Lee. S. H., Badamdor.j O., Yoon. H. B., (2019). Applying a mixed method design for needs assessment of an international fellowship training program for Mongolian health professions. *Korean J Med Educ*; 31(3):227–237. doi:10.3946/kjme.2019.133.

Ashby, J., Foster, C., Garvey, L., Wan, T., Allsop, J., Paramesparan, Y., Taylor-Robinson, S.D., Fidler, S., & Winston A. (2015). Cerebral function in perinatally HIV-infected young adults and their HIV-uninfected sibling controls, HIV Clinical Trials,16:2,81-87, DOI: 10.1179/1528433614Z.0000000003

Bello, S.I., and Bello, I.K. (2014). “Quality of life of HIV/AIDS patients in a secondary health care facility,” Proceedings (Baylor University Medical Center), vol. 26, no. 2, pp. 116–119, 2013.

Bucek, A., Leu, S. B., Warne, P. (2018). Psychiatric Disorders, Antiretroviral Medication Adherence, and Viremia in a Cohort of Perinatally HIV-Infected Adolescents and Young Adults. The Pediatric Infectious Disease Journal. 37(7):673–677.

Hawkins, A., Evangeli, M., Sturgeon, K., Le Prevost, M., Judd A. & on behalf of the AALPHI Steering Committee. (2016). Episodic medication adherence in adolescents and young adults with perinatally acquired HIV: a within-participants approach, AIDS Care, 28:sup1, 68-75, DOI: 10.1080/09540121.2016.1146210

Hipolito, R. L. and de Oliveira, D. C., “Quality of Life of people living with HIV/AIDS: a cross-sectional study,” Brazilian Journal of Nursing, vol. 15, pp. 575–578, 2016.

Anabwani, G., Karugaba, G., and Gabaitiri, L., (2016). Health, schooling, needs, perspectives and aspirations of HIV infected and affected children in Botswana: a cross-sectional survey.*BMC Pediatrics*, 16:106. DOI: 10.1186/s12887-016-0643-5.

Andrinopoulos, K., Clum, G., Murphy, D. A., Harper, G., Perez, L., Xu, J., … Adolescent Medicine Trials Network for HIV/AIDS Interventions (2011). Health related quality of life and psychosocial correlates among HIV-infected adolescent and young adult women in the US. *AIDS education and prevention: official publication of the International Society for AIDS Education*, *23*(4), 367–381. doi:10.1521/aeap.2011.23.4.367

Astuti, N., Maggiolo, F. (2014). Single-tablet regimens in HIV therapy. *Infect Dis Ther*, 3: 1-17.

Bakas, T., McLennon S. M., Carpenter J. S., Buelow J. M., Otte J. L., Hanna K. M., Ellett M. L., Hadler, K. A., Welch, J. L. Systematic review of health-related quality of life models. *Health Qual Life Outcomes*,10:134. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3548743/

Bakiono, F., Ouédraogo, L., Sanou, M., Samadoulougou, S., Guiguemdé, P.W., Kirakoya-Samadoulougou, F., Robert, A. (2014). Quality of life in people living with HIV: a cross-sectional study in Ouagadougou, Burkina Faso. Springerplus 3(372).

Bakiono, F., Wendpouiré, P., Guiguimdé, L., Sanou, M., Ouédraogo, L., Robert, A. (2015). Quality of life in persons living with HIV in Burkina Faso: a follow-up over 12 months. *BMC Public Health,* 15:1119. DOI 10.1186/s12889-015-2444-4

Barlow-Mosha, L., Eckard, A.R., McComsey, G.A., Musoke, P. (Metabolic complications and treatment of perinatally HIV-infected children and adolescents J Int AIDS Soc. 16(18600) DOI: 10.7448/IAS.16.1.18600.

Barroso, J., Leserman, J., Harmon, J. L., Hammill, B., and Pence, B. W. (2015). Fatigue in HIV-Infected People: A Three-Year Observational Study, *J Pain Symptom Manage*, 50(1): 69–79. doi:10.1016/j.jpainsymman.2015.02.006

Battles, H. B., & Wiener, L. S. (2002). From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. Journal of Adolescent Health, 30(3), 161-168.

Bekele, T., Rourke, S. B., Tucker, R., Greene, S., Sobota, M., Koornstra, J., . . . Watson, J. (2013). Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS. AIDS Care, 25(3), 337-346.

Kovacevic, Belak., Vurusic, S., and Duvancic, K. (2006). Quality of life of HIV-infected persons in Croatia. Coll Antropol; 30: 79–84.

Hult, B., Wrubel, J. R., Bränström, J., Acree, R., & Moskowitz, J. T. (2012). Disclosure and nondisclosure among people newly diagnosed with HIV: An analysis from a stress and coping perspective. *AIDS Patient Care and STDs, 26*(3), 181-190. doi:10.1089/apc.2011.0282.

Birt, L., Scott, S., Cavers, D., Campbell, C., and Walter, F., (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, 26(13) 1802–1811.

Blázquez, D., Ramos-Amador, J.T., Saínz, T. *et al.* Lipid and glucose alterations in perinatally-acquired HIV-infected adolescents and young adults. *BMC Infect Dis*15,119 (2015) doi:10.1186/s12879-015-0853-8.

Botswana Children Act. 2009. www.elaws.gov.bw

Ministry of Youth, Sports and Culture. 2010. Botswana Revised National Youth Policy.

Boudreau, M. E., Fisher, C. M. (2012). Providing effective medical and case management services to HIV-infected youth preparing to transition to adult care. *Journal of the Association of Nurses in AIDS Care*, 23(4):318-28.

Bowling, A. (2001). Measuring disease: A review of disease-specific quality of life measurement scales. 2nd ed. Berkshire: Open University Press, p. 2–7.

Briongos-Figuero, L., S., BachillerLuque, P., Palacios Martin T., Gonzalez Sagrado, M., EirosBouza. J.M. (2011). Assessment of factors influencing health-related quality of life in HIV-infected patients. HIV Med.;12(1):22–30.

Brown, L. K., Whiteley, L., Harper, G. W., Nichols, S., Nieves, A., & ATN 086 Protocol Team for The Adolescent Medicine Trials Network for HIV/AIDS Interventions (2015). Psychological symptoms among 2032 youth living with HIV: a multisite study. *AIDS patient care and STDs*, *29*(4), 212–219. doi:10.1089/apc.2014.0113

Bucciardini, R., Pugliese, K., Weimer, L., Digregorio, M., Fragola, V., Mancini, M., ... Floridia, M. (2014). Relationship between health-related quality of life measures and high HIV viral load in HIV-infected triple-class-experienced patients. HIV Clinical Trials, 15(4), 176-183. https://doi.org/10.1310/hct1504-176.

Bucek, A., Mellins, C. A., and Abrams, E. J. (2019). Helping youth with perinatal HIV thrive: Lessons learned from the first generation of youth living with perinatal HIV infection. American Psychological Association.

Bundock, H., Fidler, S., Clarke, S., Holmes-Walker, D. J., Farrell, K., McDonald, S., et al. (2011). Crossing the divide: Transition care services for young people with HIV-their views. *AIDS Patient Care & STDs*, 25(8):465-73.

Bunjoungmanee, P., Chunloy, K., Tangsathapornpong, A., Khawcharoenporn, T., Apisarnthanarak, A. (2014). Quality of life assessment among patients living with HIV/AIDS at a tertiary care hospital in Thailand. Southeast Asian JTrop Med Public Health; 45:834–42.

Burch, P. E., Heinrich, C. J. (2015). *Mixed Methods for Policy Research and Program Evaluation*. Thousand Oaks, CA: SAGE.

Catherine, N. L., Hulgan, T., Tseng, C., Milne, G. L., Lake, J. E., Landay, A. (2017) Urine Eicosanoids in the Metabolic Abnormalities, Telmisartan, and HIV Infection (MATH) Trial.*PLOS ONE,* 12(1). DOI: 10.1371/journal.pone.0170515.

Chinyere, M., Aguocha, R. U., Uwakwe, C. B., Duru, K.C., Diwe, J.K., Aguocha, O., Enwere, O., Emmanuel O. O. Prevalence and Socio-demographic Determinants of Depression among Patients Attending HIV/AIDS Clinic in a Teaching Hospital in Imo State, Nigeria. *American Journal of Medical Sciences and Medicine*. 2015; 3(6):106-112. DOI: 10.12691/ajmsm-3-6-4.

Clatworthy, J., Harding, R., Whetham, J., Consortium, E., Cooper, V. (2017). Measuring quality of life among people living with HIV: a systematic review of reviews. *Health and Quality of Life Outcomes*,15:220. DOI 10.1186/s12955-017-0778-6.

Cohen, M., Chen, Y., McCauley, M., et al. (2015). Final results of the HPTN 052 randomized controlled trial: antiretroviral therapy prevents HIV transmission. IAS 2015. 8th Conference on HIV Pathogenesis, Treatment and Prevention. July 19-22, 2015. Vancouver. Abstract MOAC0101LB, p.8. http://www.ias2015.orghttp://www.ias2015.org/WebContent/File/IAS_2015__MED2.pdf.

Cohen, S., Ter Stege, J.A., Geurtsen, G.J., et al. (2014). Poorer cognitive performance in perinatally HIV-infected children versus healthy socioeconomically matched controls. Clin Infect Dis 2014; 60:1111–9.

Cohen, M. S., Chen, Y. Q., McCauley, M. et al. (2001). Prevention of HIV-1 infection with early antiretroviral therapy. *Engl J Med*, 365: 493-505

Cooper, V., Clatworthy, J., Harding, R. *et al.* Measuring quality of life among people living with HIV: a systematic review of reviews. *Health Qual Life Outcomes* 15, 220 (2017) doi:10.1186/s12955-017-0778-6.

Creswell, J. W. (2013). Qualitative Inquiry and Research Design: Choosing Among Five Approaches. 3rd ed. Thousand Oaks, CA: Sage.

Creswell, J. W. (2014). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. 4th edition. Thousand Oaks, CA: Sage Publications.

Creswell, J. W. (2015). A Concise Introduction to Mixed Methods Research. Thousand Oaks, CA: Sage.

Creswell, J. W. and Creswell, J. D. (2018). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. 5th edition. Thousand Oaks, CA: Sage.

Creswell, J. W., Plano Clark, V. L., (2011). *Designing and conducting mixed methods research*. (2nd Ed.). Thousand Oaks, CA: Sage.

Cronje, J. H., Williams, M., Steenkamp, L., Venter, D. & Elkonin, D. (2017). The quality of life of HIV-infected South African university students: Experiences with the WHOQOL-HIV BREF, AIDS Care, 29:5, 632-635, DOI: 10.1080/09540121.2016.1234688 http://dx.doi.org/10.1080/09540121.2016.1234688

Da Silva, J., Bunn, K., Bertoni, R.F., Neves, O.A., Traebert, J. (2013). Quality of life of people living with HIV. AIDS Care; 25:71–6.

Danel, C., Moh, R., et al. (2015). TEMPRANO ANRS 12136 Study Group. A trial of early antiretrovirals and isoniazid preventive therapy in Africa. *N Engl J Med,* 373: 808-822.

Dapena, M., Jiménez, B., Noguera-Julian, A., et al. (2012). Metabolic disorders in vertically HIV-infected children: future adults at risk for cardiovascular disease. *Journal of Pediatric Endocrinology and Metabolism*, 25(5-6), pp. 529-535.

De Santis, C. E., Lin, C. C., Mariotto, A. B., Siegel, R. L., Stein, K. D., Kramer, J. L., Alteri, R., Robbins, A. S., Jemal, A., (2014). Cancer Treatment and Survivorship

Statistics.https://doi.org/10.3322/caac.21235.Https://onlinelibrary.wiley.com/doi/epdf/10.3322/caac.21235

De Vaus, D. A. (2014). Surveys in Social Research. (6th ed). Australia: UCL Press.

Degroote, S., Vogelaers, D., Vandijck, D.M. (2014). What determines health-related quality of life among people living with HIV: an updated review of the literature. Arch Pub Health;72(1):40.

Dimala, C.A., Atashili, J., Mbuagbaw, J.C., Wilfred, A., Monekosso, G.L. (2016) Prevalence of Hypertension in HIV/AIDS Patients on Highly Active Antiretroviral Therapy (HAART) Compared with HAART-Naïve Patients at the Limbe Regional Hospital, Cameroon. PLoS ONE 11(2): e0148100.doi:10.1371/journal.pone.0148100

Drake, Lesley., Woolnough., Alice., Burbano., Carmen., Bundy., Donald., (2016). Global School Feeding Sourcebook: Lessons from 14 Countries. London Imperial College Press. https://openknowledge.worldbank.org/handle/10986/24418

Earnshaw, V., Smith, l. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV Stigma Mechanisms and Well-being among PLW: a test of the HIV Stigma Framework. AIDS and Behavior, 17(5), 1785–1795. doi:10.1007/s10461-013-0437-9.

Lowenthal, E. D., Bakeera-Kitaka, S., Chapman, J., Goldrath, Kathryn., and Ferrand R.A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. Lancet Infect Dis.: 627–639. doi:10.1016/S1473-3099(13)70363-3.

Erikson, E. H. (1994). *Identity: Youth and crisis* (No. 7). WW Norton & Company

Etenyi, J. O., Okalebo, F. A., Oluka, M., Sinei, K. A., Osanjo, G. O., Kurdi, A., Meyer, J. C., Godman, B., Opanga, S. (2018). Comparison of zidovudine and tenofovir based regimens with regard to health-related quality of life and prevalence of symptoms in HIV patients in a Kenyan referral hospital. *Frontiers in Pharmacology*, 9:984.

Eustace, R. W., & Ilagan, P. R. (2010). HIV disclosure among HIV positive individuals: a concept analysis. J AdvNurs, 66(9), 2094-2103. doi: 10.1111/j.13652648.2010.05354.x

Ene, L., Franklin, D.R., Burlacu, R., Luca, A.E., Blaglosov, A.G., Ellis, R.J., Terry, J.A., Umlauf, A., Grant, I., Duiculescu, D.C., Achim, C.L., and Marcotte, T.D. (2014). Neurocognitive functioning in a Romanian cohort of young adults with parenterally-acquired HIV-infection during childhood. J Neurovirol.; 20(5): 496–504. doi: 10.1007/s13365-014-0275-1.

Fair, C. D., Sullivan, K., Dizney, R., Stackpole, A. (2014). Knowledge of disease markers and quality of patient-provider interaction among adolescents with perinatally acquired HIV: Implications for transition to adult care. *Vulnerable Children and Youth Studies*, 9(2):167-73.

Feranil, I., Herstad, B., Jallow, W., and Mbuya-Brown, R. (2010). *Assessing Implementation of Botswana's Program for Orphans and Vulnerable Children*. Washington, DC: Futures Group, Health Policy Initiative, Task Order 1.

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. Journal of Nursing Scholarship, 37, 336–342. Adapted from Wilson, I.B., & Cleary, P.D (1995). Linking Clinical Variables with Health-Related Quality of Life: A Conceptual Model of Patient Outcomes. JAMA. 273, 59–65.

Fontana, A., and Frey, J., 1994. The Art of Science. Pp. 361-76 in The Handbook of Qualitative Research, edited by N. a. Y. L. Denzin. Thousand Oaks: Sage Publications.

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. The Qualitative Report, 20(9), 1408-1416. Retrieved from http://www.nova.edu/ssss/QR/QR20/9/fusch1.pdf

Gaida, R., Truter, I., Grobler, C., Kotze, T., Godman, B. (2016). A review of trials investigating efavirenz-induced neuropsychiatric side effects and the implications. Expert Rev Anti Infect Ther. ;14(4):377-88. doi: 10.1586/14787210.2016.1157469.

Gale, N.K., Heath, G., Cameron, E. et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 13, 117 (2013) doi:10.1186/1471-2288-13-117

Garvie, P.A., Zeldow, B., Malee, K., et al. (2014). Discordance of cognitive and academic achievement outcomes in youth with perinatal HIV exposure. Pediatr Infect Dis J 33:e232–8.

George, S., Bergin, C., Clarke, S., Courtney, G., Codd, M.B. (2016). Health-related quality of life and associated factors in people with HIV: an Irish cohort study. Health and Quality of Life Outcomes 14:115 DOI 10.1186/s12955-016-0517-4.

Government of Botswana. Ministry of Finance and Development Planning. 2017. National Development Plan 11(2017-2023). https://library.wur.nl/ojs/index.php/Botswana_documents/article/view/16024

Government of Botswana Ministry of Health and Wellness. Handbook of the Botswana 2016 Integrated HIV Clinical Care Guidelines.

Government of Botswana. Ministry of Local Government and Rural Development.

https://www.unicef.org/evaldatabase/files/Assesment_of_OVC_Programme_Print_Botswana_2016-001.pdf

Government of Botswana. (2016). Ministry of Local Government and Rural Development.

Government of Botswana. (2010). The Essential Health Service Package for Botswana.

Government of Botswana. Ministry of Youth Sports and Culture. National Action Plan for Youth. 2010-2016

Government of Botswana. (2002). Revised National Policy on Destitute Persons.

Guetterman, T. C., Fetters, M. D., Creswell, J. W., (2015). Integrating Quantitative and Qualitative Results in Health Science Mixed Methods Research Through Joint Displays. *Ann Fam Med*; 13(6):554–561. Doi:10.1370/afm.1865.

Gunther, M., Foisy, M., Houston, S., Guirguis, L., & Hughes, C. (2014). Treatment beliefs, illness perceptions, and non-adherence to antiretroviral therapy in an ethnically diverse patient population. International Journal of Clinical Pharmacy, 36(1), 105-111.

Hackett, A., Strickland, K., (2018). Using the framework approach to analyse qualitative data: a worked example. *Nurse Researcher*. Doi:10.7748/nr.2018.e1580.
Halcomb, E. & Hickman, L. (2015). Mixed methods research. Nursing Standard: promoting excellence in nursing care, 29 (32), 41-47. http://dx.doi.org/10.7748/ns.29.32.41.e8858.

Harrison, K. M., Song, R., Zhang, X. (2010). Life expectancy after HIV diagnosis based on national HIV surveillance data from 25 states, United States. *J Acquir Immune DeficSyndr*, 53(1):124-30.

Havighurst, R. J. (1953). Developmental Tasks and Education. 3rd edition. New York: D. McKay.

Heale, R., James, S., Wenghofer, E., et al. (2018). Nurse practitioner's perceptions of the impact of the nurse practitioner-led clinic model on the quality of care of complex patients. *Prim Health Care Res D;* 19:553–60. Doi: 10.1017/S1463423617.

Hoare, J., Fouche, J.P., Phillips, N., et al. 2015. Clinical associations of white matter damage in ART-treated HIV-positive children in South Africa. J Neurovirol.; 21(2):120– 128.

Huynh, A. K., Kinsler, J. J., Cunningham, W. E., & Sayles, J. N. (2013). The role of mental health in mediating the relationship between social support and optimal ART adherence. AIDS Care, 25(9), 1179-1184.

Ivankova N. V., Kawamura Y. (2010). Emerging trends in the utilization of integrated designs in the social, behavioural, and health sciences. *In: Tashakkori A, Teddlie C, eds.*

Ivankova, N. V. (2006). Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice. *Field Methods,* 3-20.

Johnson, R. B., Onwuegbuzie, A. J., Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.

Johnson. B., Christensen. L., (2012). *Educational Research, Qualitative, Quantitative and Mixed Approach*. (4th Ed). California: SAGE Publication.

Joppe, M. (2000). The Research Process. *The Quantitative Report Journal*, 8(4), 597-607.

Davey J.D., Abrahams Z., Feinberg M., Prins M., Serrao C., MedeossiB., Darkoh. (2018). Factors associated with recent unsuppressed viral load in HIV-1-infected

patients in care on first-line antiretroviral therapy in South Africa. Int J STD AIDS, 29(6), 603-610. doi: 10.1177/0956462417748859. 956462417748859

Kacanek, D., Angelidou, K., Williams, P.L., Chernoff, M., Gadow, K.D., Nachman, S. (2015). International Maternal Pediatric Adolescent AIDS Clinical Trials Group (IMPAACT) P1055 Study Team. Psychiatric symptoms and antiretroviral nonadherence in US youth with perinatal HIV: a longitudinal study. AIDS.;29(10):1227–1237pmid:26035322.

Kaji, A.H., Schriger, D., Green, S. (2014). Looking through the retrospectoscope: Reducing bias in emergency medicine chart review studies. Ann Emerg Med. Sep;64(3):292-8. DOI: 10.1016/j.annemergmed.2014.03.025.

Kalemeera, F., Mbango, C., Mubita, M., Naikaku, E., Gaida, R., Godman, B. (2016). Effect of changing from first- to second-line antiretroviral therapy on renal function: a retrospective study based on data from a single health facility in Namibia. *Expert Review of Anti-Infective Therapy,* 14(8), 777-83.

Kalichman, S. C., Pellowski, J., Kalichman, M. O., Cherry, C., Detorio, M., Caliendo, A. M., & Schinazi, R. F. (2011). Food insufficiency and medication adherence among people living with HIV/AIDS in urban and peri-urban settings. Prevention Science, 12, 324-332. doi:10.1007/s11121-011-0222-9

Karkashadze, E., Gates, M. A., Chkhartishvili, N., DeHovitz, J., and Tsertsvadze, T. (2017). Assessment of quality of life in people living with HIV in Georgia. *International Journal of STD & AIDS*, (7) 672–678. DOI: 10.1177/0956462416662379.

Kaur, M. (2016). Application of Mixed Method Approach in Public Health Research. *Indian journal of community medicine*: *official publication of Indian Association of Preventive & Social Medicine*, 41(2), 93–97. doi:10.4103/0970-0218.173495.

King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayiwa, S., Abang, B., Babirye, F., Lindkvist, P., Johansson, E., Mermin, J., Bunnell, R. (2008) Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. AIDS Behav. 2008 Mar; 12(2):232-43.

Ko, H. C., Wang, L. L., & Xu, Y. T. (2013). Understanding the different types of social support offered by audience to A-list diary-like and informative bloggers. *Cyberpsychology, behavior and social networking*, *16*(3), 194–199. doi:10.1089/cyber.2012.0297

Kotzé, M., Visser, M., Makin, J., Sikkema, K., & Forsyth, B. (2013). Psychosocial variables associated with coping of HIV-positive women diagnosed during pregnancy. AIDS and Behavior, 17(2), 498-507.

Laughton, B., Cornell, M., Boivin, M., Van Rie, A. (2013). Neurodevelopment in perinatally HIV-infected children: a concern for adolescence. Journal of the International Aids Society; 16: 18603.
Lavelle, E., Vuk, J. & Barber, C. (2013). Twelve tips for getting started using mixed methods in medical education research. *Medical Teacher*, *35*, 272-276.

Leedy, P., Ormrod, J. E. (2014). *Practical Research Planning and Design*. (10th Ed).

Edinburgh: Pearson Educational Inc.

Lesley, D., Alice, W., Carmen, B., Donald, B.(2016)*Global School Feeding Sourcebook: Lessons from 14 Countries.* London: Imperial College Press. © Lesley Drake.
Letamo, G., Navaneetham, K. (2014). Prevalence and Determinants of Adult Under-Nutrition in Botswana. *PLoS ONE,* 9(7). DOI: 10.1371/journal.pone.0102675.

Lewden, C., Salmon, D., Morlat, P., Bevilacqua, S., Jougla, E., Bonnet, F., et al. (2005). Causes of death among human immunodeficiency virus (HIV)-infected adults in the era of potent antiretroviral therapy: emerging role of hepatitis and cancers, persistent role of AIDS. *Int J Epidemiol*, 34(1):121-30.

Lewis-de Los Angeles, C.P., Alpert, K.I., Williams, P.L., et al. (2016). Deformed subcortical structures are related to past HIV disease severity in youth with perinatally acquired HIV infection. J Pediatric Infect Dis Soc.;5(suppl 1): S6–S14.

Lichtman, M. 2013. Qualitative Research in Education. A User´s Guide (3d ed.), London, Sage. Quoted in Carla Dimitre Dias Alves1, Maria de Nazaré Castro Trigo Coimbra1, Teacher Training and the Development of First Language Reading Strategies. American Journal of Educational Research. 2014, Vol. 2 No. 11, 1044-1049. DOI: 10.12691/education-2-11-7.

Lin, M. K., Wu, A. W., Revicki, D. A. (2002). Incorporating quality of life measures in HIV clinical trials.*HIV Clin Trials*, 3(3):202-18.

Lipshultz, S.E., Miller, T.L., Wilkinson, J.D., Scott, G.B., Somarriba, G., Cochran, T.R., et al. (2013). Cardiac effects in perinatally HIV-infected and HIV-exposed but uninfected children and adolescents. J Int AIDS Soc. 16(18597) doi: 10.7448/IAS.16.1.18597.

Lorenz, K.A., Cunningham, W.E., Spritzer, K.L. et al. Qual Life Res (2006) 15: 951. https://doi.org/10.1007/s11136-005-6010-x. https://doi.org/10.1007/s11136-005-6010-x

Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *Lancet Infect Dis*, 14(7): 627–639. doi:10.1016/S1473-3099(13)70363-3.

Liping, M., Peng, X., Haijiang, L., Lahong, J., and Fan, L. (2015). “Quality of life of people living with HIV/AIDS: a Cross-sectional study in zhejiang province, China,” PLoS ONE, vol. 10, no. 8, Article ID e0135705.

Malee, K., Williams, P.L., Montepiedra, G., et al. (2009). The role of cognitive functioning in medication adherence of children and adolescents with HIV infection. J Pediatr Psychol 2009; 34:164–75.

Malee, K.M., Smith, R.A., Mellins, C.A. (2016). Pediatric HIV/AIDS Cohort Study. Brain and cognitive development among U.S. youth with perinatally acquired human immunodeficiency virus infection. J Pediatric Infect Dis Soc.;5(suppl 1): S1–S5.

Mannheimer, S. B., Matts, J., Telzak, E., Chesney, M., Child, C., Wu, A. W., et al. (2005). Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence. *AIDS Care*, 17(1):10-22. http://dx.doi.org/10.4102/sajhivmed.v17i1.475

Martinez, J., Harper, G.W., Carleton, R.A., Hosek, S.G., Bojan, K., Clum, G., Ellen, J., and ATN. 2012. The impact of stigma on medication adherence among HIV-positive adolescent and young adult females and the moderating effects of coping and satisfaction with health care. AIDS Patient Care STDS; 26:108–115.

Mataranyika, P.A., Kibuule, D., Kalemeera, F., Kaura, H., Godman, B., Rennie, T.W. (2017). Liver enzyme elevations in a cohort of HIV/ AIDS patients on first-line antiretroviral therapy in Namibia: findings and implications. Alexandria Journal of Medicine 54:49-56.

Maughan-Brown, B. (2017). The improved life expectancy of people living with HIV: who is left behind? *DOI*,4(8), 324-326.

Mays, N. & Pope, C. (1995). "Qualitative Research: Rigour and Qualitative Research." BMJ. 311(6997), 109-112. Adm Policy Ment Health. 2015 Sep; 42(5): 533–544.

Mays, N. & Pope, C. (2000). "Quality in qualitative health research" in N. Mays and C. Pope (Eds.) Qualitative Research in Health Care (2nd edition). London: BMJ Books. pp. 89-102. *Medical Research Methodology,13*, 1, 117.

Mbalinda, S.N., Kiwanuka, N., Kaye, D.K. et al. (2015). Health Qual Life Outcomes 13: 170. https://doi.org/10.1186/s12955-015-0366-6.

Meemon, N., Paek, S. C., Yenchai, D., Wan, T. T., (2016), Application of the WHOQOL-HIV BREF Questionnaire in HIV-Infected Thai Patients: Reliability and Validity of the Instrument. *The Journal of the Association of Nurses in AIDS Care,* 27(5):698-708.

Mellins, C.A., Elkington, K.S., Leu, C.S., et al. Prevalence and change in psychiatric disorders among perinatally HIV-infected and HIV-exposed youth. AIDS Care. 2012;24(8):953–962.

Mellins, C.A., and Malee K.M. (2013). Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. J Int AIDS Soc. 2013;16.

Mendoza, J. A, Matshaba, M., Makhanda, J., Liu, Y., Boitshwarelo, M., Anabwani, G. M., J Acquir Immune Defic Syndr. 2014 Aug 1;66(4):414-8. doi:10.1097/QAI.0000000000000190.

Mills, E. J., Nachega, J. B., Bangsberg, D. R., Singh, S., Rachlis, B., Wu, P., et al. (2006). Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med,*3(11).

Miners, A., Phillips, A., Kreif, Noemi A., Rodger, A., Speakman, A., Fisher, M., Anderson, J., Collins, S., Hart, G., Sherr, L., Lampe, F.C., for the ASTRA

(Antiretrovirals, Sexual Transmission Risk and Attitudes) Study. (2014). Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population.The Lancet. ages e1-e48 ; https://www.thelancet.com/journals/lanhiv/home

Monteiro, Fabiana, M., Canavarro, M. C. & Pereira, M. (2016). Factors associated with quality of life in middle-aged and older patients living with HIV, AIDS Care, 28:sup1, 92-98, DOI: 10.1080/09540121.2016.1146209.

Morse, J., Niehaus, L., (2009). Mixed method design: Principles and procedures. Walnut Creek, CA: Left Coast Press.

Mutabazi-Mwesigire, D., Katamba, A., Martin, F., Seeley, J., Wua., W. (2015). Factors That Affect Quality of Life among People Living with HIV Attending an Urban Clinic in Uganda: A Cohort Study. doi:10.1371/journal. pone.0126810.

Mutanga, J. N., Mutembo, S., Ezeamama, A. E., Song, X., Fubisha, R. C., Kapembwa, K., Sialondwe, D., Simuchembu, B., Chinyonga, J., Thuma, P. E. and Whalen, C. C., (2019). Long-term survival outcomes of HIV infected children receiving antiretroviral therapy: an observational study from Zambia (2003–2015). BMC Public Health, 19: 115.https://doi.org/10.1186/s12889-019-6444-7

Mafirakureva, B., Dzingirai, M.J., Postma, M., van Hulst & Khoza S. (2016). Health-related quality of life in HIV/AIDS patients on antiretroviral therapy at a tertiary care facility in Zimbabwe, AIDS Care, 28:7, 904-912, DOI: 10.1080/09540121.2016.1173639.

Ndubuka, N.O., Lim, J. H., Van der Wal, D. M., Ehlers, J. V., Health-related quality of life of antiretroviral treatment defaulters in Botswana, South. Afr. Johannesburg, Southern African Journal of HIV Medicine On, 17(1).

Nichols, S.L., Chernoff, M.C., Malee, K.M., et al. Executive functioning in children and adolescents with perinatal HIV infection and perinatal HIV exposure. J Pediatric Infect Dis Soc 2016; 5 (Suppl 1): S15–23.

Nnyepi, M., Bennink, M., Jackson-Malete, J., Venkatesh, S., Malete, L., Mokgatlhe, L., Lyoka, P., Anabwani, G., Makhanda, J. and Weatherspoon, L. (2015). Nutrition status of HIV+ children in Botswana. *Health Education*, 115(5) 495-514.

Noble, H., Smith, J. (2015). Issues of validity and reliability in qualitative research. *BMJ Evidence Based Nursing*, 18. http://dx.doi.org/10.1136/eb-2015-102054.

Nobre, N., Pereira, M., Roine, R. P., Sintonen, H., & Sutinen, J. (2017) Factors associated with the quality of life of people living with HIV in Finland. AIDS Care, 29(8), 1074- 1078.

O'Connell, K. A., Skevington, S. M. (2012). An international quality of life instrument to assess wellbeing in adults who are HIV-positive: A short form of the WHOQOL-HIV (31 items). *AIDS and Behavior*, 16(2), 452-460. https://doi.org/10.1007/s10461-010-9863-0.

Olson, B., Vincent, W., Meyer, J.P. *et al.* Depressive symptoms, physical symptoms, and health-related quality of life among older adults with HIV. *Qual Life Res*28, 3313– 3322 (2019) doi:10.1007/s11136-019-02271-0

Osinde, M. O., Kakaire, O., & Kaye, D. K. (2012). Factors associated with disclosure of HIV serostatus to sexual partners of patients receiving HIV care in Kabale, Uganda.*Int J Gynaecol Obst et*, 118(1), 61-64. DOI: 10.1016/j.ijgo.2012.02.008.

Palella, F. J., Delaney, K. M., Moorman, A.C., Loveless, M. O., Fuhrer, J., Satten, G. A., et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med*, 338(13), 853-60.

Palinkas L.A., Purposeful sampling for qualitative data collection and analysis in mixed method implementation research, *Qualitative Research in Psychology,13, 2*, 109-129.

Pantelic, M., Boyes, M., Cluver, L., & Thabeng, M. (2016). 'They Say HIV is a Punishment from God or from Ancestors': Cross-Cultural Adaptation and Psychometric Assessment of an HIV Stigma Scale for South African Adolescents Living with HIV (ALHIV-SS). Child Indicators Research, 11(1), 207-223. doi:10.1007/s12187-016-9428-5.

Parahoo, K. (2014). *Nursing Research: Principles, Process and Issues*. Third edition. Palgrave, Hampshire.

Parkinson, S., Eatough, V., and Holmes, J., Stapley, E., Target, M., and Midgley, N. (2016). Framework analysis: a worked example of a study exploring young people's experiences of depression. Qualitative Research in Psychology 13 (2), pp. 109-129. ISSN 1478-0887.

Patton, M. (2015) Qualitative Research and Evaluation Methods. 4th Edition, Sage Publications, Thousand Oaks.

Paul, V. W., Gardner, D. C., and Haeffele, L. M. (2012). *When to Use What Research Design*. New York: Guilford.

Pellowski, J. A., Kalichman, S.C., Matthews, K. A., & Adler, N. (2013). A pandemic of the poor: Social disadvantage and the U.S. HIV epidemic. American Psychologist, 68, 197-209. doi:10.1037/a0032694

Phaladze, N.A., Human, S., Dlamini, S.B., Hulela, E.B., Hadebe, I.M., Sukati, N.A., et al. (2005). Quality of life and the concept of 'living well' with HIV/AIDS in sub-Saharan Africa. J Nurs Scholarship. 2005; 37:120–6. https://doi.org/10.1111/j.1547-5069.2005.00023.x

Piajet, J., 1952, The Origin of Intelligence in Children, International University Press, New York.

Prince, S. A., Saunders, T.J., Gresty, K., and Reid, R. D. (2014). A Comparison of the effectiveness of physical activity and sedentary behavior interventions in

reducing sedentary time in adults: a systematic review and meta-analysis of controlled trials. Obes Rev. 2014 15(11): 905–919. DOI: 10.1111/obr.12215.

Redmond, S.M., Tzy-Jyun, Y., Russell, J.S., et al. (2016). Longitudinal evaluation of language impairment in youth with perinatally acquired HIV and youth with perinatal HIV exposure. J Pediatric Infect Dis Soc; 5 (Suppl 1): S33–40.

Republic of Botswana. (1994). The Revised National Policy on Education. Government Paper; no. 2 of 1994. www.gov.bw

Republic of Botswana. (2009). Botswana Children. www.elaws.gov.bw/lawhome.php

Republic of Botswana. (2018). Third National HIV and AIDS Strategic Framework (2018 – 2023). www.gov.bw

Ritchie, J., Lewis, J., (2003). Qualitative Research Practice: A Guide for Social Science Students and Researchers. Sage, London.

Rodger, A.J., Cambiano, V., Bruun, T., et al. (2016). Sexual activity without condoms and risk of HIV transmission in sero-different couples when the HIV-positive partner is using suppressive antiretroviral therapy. *JAMA.* 2016; 316: 171-181.

Rueda S, Raboud J, Mustard C, Bayoumi A, Lavis J, Rourke S (2011) Employment status is associated with both physical and mental health quality of life in people living with HIV. AIDS Care 23(4): 435–443. https://doi.org/10.1080/09540121.2010.507952

Rydström, L.-L., Ygge, B.-M., Tingberg, B., Navér, L. & Eriksson, L. E. (2013). Experiences of young adults growing up with innate or early acquired HIV infection—a qualitative study. Journal of Advanced Nursing, 69(6), pp. 1357-1365. DOI: 10.1111/j.1365-2648. 2012. 06127.x.

Saunders, B., Sim, J., Kingstone, T. et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 52, 1893–1907 (2018) doi:10.1007/s11135-017-0574-8

Shan, D., Ge, Z., Ming, S. et al. (2011). “Quality of life and related factors among HIV-positive spouses from serodiscordant couples under antiretroviral therapy in Henan Province, China,” PLoS ONE, vol. 6, no. 6, Article ID e218

Shanahan, M.J. 2000. Pathways to Adulthood in Changing Societies. Variability and Mechanisms in Life Course Perspective. Annual Review of Sociology; 26 (1): 667-692

Sirois, P.A., Chernoff, M.C., Malee, K.M., et al. (2016). Associations of memory and executive functioning with academic and adaptive functioning among youth with perinatal HIV exposure and/or infection. J Pediatric Infect Dis Soc; 5 (Suppl 1): S24–32.

Smit, M., Brinkman, K., Geerlings, S., Smit, C., Thyagarajan, K., Sighem, A. V., de Wolf, F., Hallett, T. B., ATHENA observational cohort (2015). Future challenges for clinical care of an aging population infected with HIV: a modelling study. *The Lancet Infectious Diseases,* 15(7), 810-818.

Statistics Botswana. (2014). Botswana AIDS Impact Survey IV: Statistical Report.

Statistics Botswana. (2018). Education Statistics Brief - 2015. www.statsbots.org.bw

Stephen, G. (2013). *Research Design: Creating Robust Approaches for the Social Sciences*. Thousand Oaks, CA: Sage.

Subedi, D. (2016). Explanatory Sequential Mixed Method Design as the Third Research Community of Knowledge Claim. *American Journal of Educational Research*, 4(7), pp 570-577. http://pubs.sciepub.com/education/4/7/10.

Sundh, J., Johansson, G., Larsson, K., Lindén, A., Löfdahl, C. G., Janson, C., Sandström, T. (2015). Co-morbidity and health-related quality of life in patients with severe chronic obstructive pulmonary disease attending Swedish secondary care units. *Int J Chron Obstruct Pulmon Dis*, 10:173-83.

Sweeney, S.M., Vanable, P.A. (2016). The Association of HIV-Related Stigma to HIV Medication Adherence: A Systematic Review and Synthesis of the Literature. *AIDS Behav. Jan; 20(1):29-50.*

Tanner, A. E., Philbin, M. M., Chambers, B. D., Ma, A., Hussen, S., Ware, S., ... Fortenberry, J. (Accepted/In press). Healthcare Transition for Youth Living with HIV. *Journal of Adolescent Health*. https://doi.org/10.1016/j.jadohealth.2018.02.004

Tavakol, M., Dennick, R., (2011) "Making sense of Cronbach's Alpha" Int J Med Educ; 2: 53–55. Doi: 10.5116/ijme.4dfb.8dfd

Tesfay, A., Gebremariam, A., Gerbaba, G., and Abrha, H. (2015). "Gender differences in health related quality of life among people living with HIV on highly active antiretroviral therapy in Mekelle town, northern Ethiopia," BioMed Research International, vol. 2015, Article ID 516369, pp. 1–9.

Tesfaye, M., Olsen, M. F., Medhin, G., Friis, H., Hanlon, C., Holm,L. (2016). Adaptation and validation of the short version WHOQOL-HIV in Ethiopia. *International Journal of Mental Health Systems,* 10:29.

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychol Med*, 28:551–8.

The WHOQOL HIV Group. Initial steps to developing the World Health Organization's Quality of Life Instrument (WHOQOL) module for international assessment in HIV/AIDS. AIDS Care. 2003;15(3):347-57.

Thomas, D. R. (2017). Feedback from research participants: are member checks useful in qualitative research? Qualitative Research in Psychology, 14:1, 23-41, DOI: 10.1080/14780887.2016.1219435

Thoth, C. A., Tucker, C., Leahy, M., & Stewart, S. M. (2014). Self-disclosure of serostatus by youth who are HIV positive: A review. Journal of Behavioral Medicine, 37(2),276-288.

Tran, B.X., Ohinmaa, A., Nguyen, L.T., et al. (2012). "Gender differences in quality of life outcomes of HIV/AIDS treatment in the latent feminization of HIV epidemics in

Vietnam," AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV, vol. 24, no.10, pp.1187–1196.

Trankle, S. A. et al. (2019). "Integrating health care in Australia: a qualitative evaluation." BMC health services research vol. 19,1 954. doi:10.1186/s12913-019-4780-z.

Turan, J.M., Atkins, G., Kempf, M.C., Clay, O.J., Raper, J.L., Mugavero, M.J., Turan B. (2017). Interpersonal Mechanisms Contributing to the Association Between HIV-Related Internalized Stigma and Medication Adherence. *Blake Helms C, AIDS Behav.; 21(1):238-247.*

UN General Assembly A/RES/64/142. (2010). United Nations Guidelines for the Alternative Care of Children.

United Nations General Assembly. (2015). Transforming our world: the 2030 Agenda for Sustainable Development. https://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E.

Vagiri, R. V., Meyer, J. C., Godman, B., & Gous, A. G. S. (2018). Relationship between adherence and health-related quality of life among HIV-patients in South Africa: findings and implications. Journal of AIDS and HIV Research, 10(8), 121-132.https://academicjournals.org/journal/JAHR/article-abstract/DF15B5159645

Vassar, M., and Holzmann, M. (2014). The retrospective chart review: important methodological considerations. J Clin Diagn Res. 2014 Sep; 8(9): JG01–JG04. doi: 10.7860/JCDR/2014/8301.4806.

Verolet, C.M., Delhumeau-Cartier, C., Sartori, M., Toma, S., Zawadynski, S., Becker, M., Bernasconi, E., Trellu, L.T., Calmy, A. 2015.Lipodystrophy among HIV-infected patients: a cross-sectional study on impact on quality of life and mental health disorders. AIDS Res Ther. doi:10.1186/s12981-015-0061-z.

Vidrine, D. J., Amick III, B.C., Gritz, E.R., and Arduino, R.C. (2005). "Assessing a conceptual framework of health-related quality of life in a HIV/AIDS population," Quality of Life Research, vol.14, no.4, pp.923–933.

Vigano, A., Cerini, C., Pattarino, G., Fason, S., Zuccotti, GV. (2010). Metabolic complications associated with antiretroviral therapy in HIV-infected and HIV-exposed uninfected paediatric patients. Expert Opin Drug Saf. 2010; 9:431–45.

Wang'ondu, R., Samuels, S., Andiman, W., Paintsil, E., Barakat. & Langs-Barlow, A. Sabater, A. (2018). Desire for improved disclosure, community and bonding among young adults with perinatally acquired HIV, Cogent Social Sciences, 4:1, DOI: 10.1080/23311886.2018.1463816.

Wanqing, Z. (2014). Mixed Methods Application in Health Intervention Research: A Multiple Case Study. *International Journal of Multiple Research Approaches,* 8:1, 24-35, DOI: 10.5172/mra.2014.8.1.24

Weintraub, A., Mellins, C.A., Warne, P. et al. (2017) Patterns and Correlates of Serostatus Disclosure to Sexual Partners by Perinatally-Infected Adolescents and Young Adults AIDS Behav 21: 129. https://doi.org/10.1007/s10461-016-1337-6.

Weaver, L.J., and Hadley, C. (2009). Moving beyond hunger and nutrition: a systematic review of the evidence linking food insecurity and mental health in developing countries. Ecol Food Nutr. 48:263–84.

Weiss, MG., Ramakrishna, J., Somma, D. (2006). Health-related stigma: rethinking concepts and interventions. *Psychol Health Med, 11*(3), 277-287. doi: V200Q46382387M12.

Weledji, E.P., Nsagha, D., Chichom, A., Enoworock, G., (2015). In Gastrointestinal surgery and the acquired immune deficiency syndrome, 4(1), 36-40.

WHO. 1946. WHO Definition of Health. Preamble to the Constitution of the WHO. Official Records of the WHO, no. 2, p. 100. Http://www.who.int/governance/eb/who_constitution_en.pdf [PDF - 335KB]

WHO. 2003. Adherence *to long-term therapies: Evidence for action*. Geneva: World Health Organisation.

WHO. 2012. WHO Discussion Paper on the development of a 2013 to 2020 Action Plan for NCDs.https://www.who.int/nmh/events/2012/action_plan_20120726.pdf?ua=1

WHO. 2015. Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Geneva, Switzerland: WHO Press.

Wilson IB, Cleary PD. (1995). Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA.; 273:59–65.

Zhu, Y., Liu, J., Qu, B. (2017). Psychometric properties of the Chinese version of the WHOQOL-HIV BREF to assess the quality of life among people living with HIV/AIDS: a cross-sectional study.

APPENDIX 1: WHOQOL-HIV BREF

ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your gender? Male / Female

How old are you? _____ (age in years)

What is the highest education you received? None at all / Primary / Secondary / Tertiary

What is your marital status? Single / married/ living as married / separated / divorced / widowed

How is your health? Very Poor / Poor / neither /Poor nor Good / Good / Very Good

Do you consider yourself currently ill? Yes / No

If there is something wrong with you, what do you think it is?

_____

Please respond to the following questions if they are applicable to you:

What is your HIV serostatus? Asymptomatic (no symptoms or illnesses) / Symptomatic (have some symptoms or illnesses) / AIDS converted (very sick)

In what year did you first test positive for HIV? _____

In what year do you think you were infected? _____

How do you believe you were infected with HIV? (Circle one only):
Sex with a man / Sex with a woman / Injecting drugs / Blood products /from mother-to-child/ Other (specify) _____

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

		Not at all	A little	A moderate amount	Very much	Extremely
11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5

You should circle the number that best fits how well you are able to concentrate over the last two weeks. So you would circle the number 4 if you were able to concentrate very much. You would circle number 1 if you were not able to concentrate at all in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Poor	Neither poor nor good	Good	Very good
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
5 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
8 (F52.2)	To what extent are you bothered by people blaming you for your HIV status	1	2	3	4	5
9 (F53.4)	How much do you fear the future?	1	2	3	4	5
10 (F54.1)	How much do you worry about death?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	extremely

11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
12 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
13 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
14 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
15 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
16 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
17 (F51.1)	To what extent do you feel accepted by the people you know?	1	2	3	4	5
18 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
19 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
		Very poor	Poor	Neither poor nor good	good	Very good
20 (F9. 1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you how good or satisfied you have felt about various aspects of your life over the last two weeks

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
21 (F3.3	How satisfied are you with your sleep?	1	2	3	4	5
22 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
23 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
24 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
25 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
26 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
27 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
28 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5

29 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
30 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
31 (F8.1)	How well are you able to get around?	1	2	3	4	5

Did someone help you to fill out this form?

How long did it take to fill this form out?

Do you have any comments about the assessment?

THANK YOU FOR YOUR HELP

APPENDIX 2: MEDICAL RECORDS REVIEW FORM

Study ID: _____

Name of Data Abstractor: _____

Source: EMR Paper File

Social-demographics:

Gender: Male Female

Age in completed years: _____

Date of birth: _____

Biological Mother: Alive not on ART Alive on ART Deceased

Place of Residence: _____

Living arrangements: _____

Anthropometrics

Height _____ Weight_____ BMI_____

Antiretroviral Regimen

Date of Initiation: _____ Current ART regimen:_____

Medication adherence (<6 months recordings)

DATE	ADHERENCE LEVEL
1.	
2.	
3.	

Viral Load and CD4 Cell Count (three most recent recordings)

DATE	VIRAL LOAD	DATE	CD4 CELL COUNT
1.		**1.**	
2.		**2.**	
3.		**3.**	

WHO CLINICAL STAGING:

Abstractor signature: _____

Date_____

APPENDIX 3: IN-DEPTH INTERVIEW GUIDE

Instruction:

- Start the interview by introducing the concept of quality of life. Explain that quality of life is the standard of health, comfort and happiness experienced by an individual. It includes everything from physical health, family, relationships, education, employment, religious beliefs, finance and the environment.
- Explain that research studies on young adults who contracted HIV from their mothers, called perinatal transmission of HIV, have shown that having HIV affects their quality of life in many ways. This study will examine how HIV affects the quality of life of young adults at Botswana-Baylor and recommend policies to promote their quality of life.

1. Tell me about yourself (probe the person to talk about education level and employment status, place of residence, living arrangements, and other social-demographic characteristics of the individual).

2. Tell me about times during your life when HIV has affected your life (probe and help the person to describe the lived experience with HIV).

3. How long have you been on ARVs? Do you have any difficulties with ARVs? If so, what difficulties? What support do you need to deal with those difficulties?

4. Are you bothered by any illness or physical problems that limit your activities of daily living?

5. How do you feel about being HIV positive? (probe to help the person express how they are coping with HIV?

6. Apart from your close family members and health care workers, who else have you disclosed to about your HIV status? If no (probe why)? If yes (Probe: Did you personally tell them?). How has your relationship with this person changed since telling them about your HIV status? Has this person helped you in dealing with your HIV status? Did you get any unsupportive reactions after disclosing your status?

7. How do you see your life in the future? Is being HIV positive a challenge? Do you have any goals you want to achieve in the future?

8. Are you engaged in a romantic relationship or have you ever been engaged in a romantic relationship? If yes, have you engaged in sexual activities? Is growing up with HIV a problem? What are your needs concerning romantic relationships and sexual activity and birth control?

9. Have you considered being married or parenting? Do you have a child of your own? If yes, what is your experience with parenting?

10. How do you envision your adult care? What role can Baylor play in your adult life? What role do you want Baylor to play going forward?

11. What support do you recommend for yourself and or other YALPH to promote their HRQOL of life? (Make references to issues raised above)

APPENDIX 4: CLIENT INFORMATION LEAFLET AND INFORMED CONSENT

Name of study: Developing Policy Guidelines to Promote the Health Related Quality of Life of Young Adults Living Perinatally Acquired HIV.

Primary Researcher: Grace Karugaba

INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to ask the investigator. You may call me, Grace Karugaba, at 3190083 (office) if you have further questions. You should not agree to take part unless you are completely happy about all the procedures involved.

WHAT IS THE PURPOSE OF THE STUDY?

The study will provide information that will enable policymakers, Botswana-Baylor, policymakers and programmers to develop policies and interventions to enhance the wellbeing and quality of life of young adults living with HIV/AIDS.

WHAT WILL BE EXPECTED FROM ME?

If you decide to take part, you will be one of the young adults aged 18 to 30 years at Botswana–Baylor who will be required to fill a form and participate in an interview that has questions concerning the quality of your life. Quality of life is a measure of how a person is functioning physically, emotionally, socially, and spiritually within his or her environment. It is also a way to understand a person's level of satisfaction with his or her life given the situation in which they are living. If you participate in the interview, you will be asked some questions which will guide you to share personal experiences of certain things that are thought to affect the quality of life of young adults living with HIV.

If you agree to participate, some additional information about your health will be got from your medical records at Botswana-Baylor including your most recent Viral Load, CD4 cell count, height, and weight, medication and adherence rates. Through participating in the research, you will contribute to the body of knowledge that will be used to form policies and programs to improve the quality of life of young adults at Botswana-Baylor and elsewhere.

WHAT IS THE DURATION OF THIS STUDY?

The study will last for three months. However, completing the questionnaire will take you about 15 to 20 minutes. The interviews will last 45-60 minutes.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

The protocol of the study was approved by the Ethics Committee of the Botswana-Baylor. The study was also approved by the Health Research and Development Committee (HRDC) of the Ministry of Health and Wellness.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is voluntary; that means you do not have to be part of the study if you do not want to. If you said you will participate and you change your mind, it will be fine. You can stop any time.

WILL THE STUDY PROCEDURES HURT ME?

The study and procedures involve no foreseeable physical discomfort. However, as a participant, you may experience some sad emotions as you share your experiences or think about your quality of life. If you feel so, you need to report to the researcher who will immediately give you supportive counselling or refer you to other staff at Botswana-Baylor who will give you additional support.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

The study procedures involve no foreseeable risks to you or your family.

CONFIDENTIALITY

All information obtained during the course of this study is strictly confidential. Your identity will not be revealed when the study results are reported. All the data that has been collected will be stored in a secure place and will not be shared with any other person without your permission. The audio-taped recordings and any other data will be kept safely under lock and key.

INFORMED CONSENT

I hereby confirm that the investigator has informed me about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above-written information (patient information leaflet and informed consent) regarding the study.

I am aware that the results of the study, including personal details regarding my age, medical records, and any other information on my quality of life provided for purposes of this study will be anonymously processed into a research report.

I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Patient's name _____ (Please print)

Patient's signature _____ Date _____

Investigator's name _____ (Please print)

Investigator's signature _____ Date _____

APPENDIX 5: QUALITATIVE THEMES, SUBTHEMES AND CATEGORIES

THEMES	SUBTHEMES	CATEGORIES
BIOLOGICAL FUNCTION	Viremia and illness related worries and concerns.	Difficulties with HIV treatment; worries and anxieties about treatment failure, exacerbated illness and death; dependence on medicines.
SYMPTOMS STATUS	Physical, mental	HIV symptoms, comorbidities, other chronic illnesses (asthma, epilepsy, allergy), mental health issues (depression, stress, trauma); ART side effects; other illnesses.
FUNCTIONAL STATUS	Physical functioning	Disabilities and impairments; dissatisfaction with physical appearance and poor body image; sexual dysfunction (e.g. extensive warts, erectile dysfunction, and heavy or irregular menstruation); underweight BMI (stunting, loss of weight);
	Psychological functioning	Disclosure worries and concerns; Long standing grief, loss and bereavement;
CHARACTERISTICS OF THE INDIVIDUAL	Educational level	High educational performance and attainment: a sense of self-worth and life satisfaction, high prospects for employment, financial independence. Low educational performance and attainment : feelings of personal inadequacy, worthlessness, embarrassment; low self-esteem, fear about the future; reduced employability.
	Employment status	Employed: a sense of self-worth, good adherence to ART, financial independence. Unemployed: idleness; financial stressors; feelings of worthlessness and embarrassment; low self-esteem.
	Transitioning into adulthood	Young parents; YALPH aging out of institutional care
	Future-related worries and concerns;	Employment, marriage, financial independence, availability of free ART in the future
	Individual coping strategies	Adaptive or maladaptive coping strategies.
CHARACTERISTICS OF THE ENVIRONMENT	Social support	Availability of social support - family members, healthcare workers, peers/friends, romantic partners Lack of social support – self-isolation due to fear of stigma and discrimination, violence and conflicts, not being understood by others.
	Stigma and discrimination	Perceived stigma or experience of stigma (family, community, schools, health facility)
	Disclosure worries and concerns	Negative and positive implications of disclosure to family, friends/peers, sexual partners
	Financial stressors	Lack of financial independence (food insecurity, transport challenges, inability to meet parenting responsibilities).

PRIVATE BAG 0038
GABORONE
BOTSWANA
REFERENCE:

REPUBLIC OF BOTSWANA
MINISTRY OF HEALTH AND WELLNESS

TEL: (+267) 363 2500
FAX: (+267) 391 0947
TELEGRAMS: RABONGAKA
TELEX: 2618 CARE BD

REFERENCE NO: HPDME 13/18/1 22nd August 2018

Health Research and Development Division

Notification of IRB Review: **New application**

Grace Karugaba
Botswana-Baylor
Private Bag BR129
Gaborone

Dear Grace Karugaba

Protocol Title: **ASSESSING THE QUALITY OF LIFE OF HIV INFECTED YOUNG ADULTS AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE, GABORONE, BOTSWANA**

HRU Approval Date:	22 August 2018
HRU Expiration Date:	21 August 2019
HRU Review Type:	Expedited Review
HRU Review Determination:	Approved
Risk Determination:	Minimal risk

Thank you for submitting new application for the above referenced protocol. The permission is granted to conduct the study.

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health and Wellness within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 7A.7 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 7A7 or Ministry of Health website: www.moh.gov.bw or can be requested via e- mail from Mr. Kgomotso Motlhanka, e-mail address: kgmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

If you have any questions please do not hesitate to contact Ms S. Mosweunyane at smosweunyane@gov.bw Tel: 3632018 and Mr Kgomotso Motlhanka at kgmotlhanka@gov.bw at 3632751. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours faithfully

Mr M. Keetile
for/PERMANENT SECRETARY

MINISTRY OF HEALTH
RESEARCH DIVISION
2016 -09- 22
REPUBLIC OF BOTSWANA

Botswana-Baylor
Children's Global Centre of Excellence
An Affiliate of Baylor College of Medicine International Pediatric AIDS Initiative at Texas Children's Hospital

Plot: 1826, Hospital Way
Off Notwane Road
Private Bag BR329 Gaborone
Tel: (+267) 319-8081
Fax: (+267) 319-0079
Website: www.bhcpi.org

DATE: 19/12/2019

TO: Grace Karugaba

FROM: Botswana-Baylor COE Institutional Review Board

PROJECT TITLE: ASSESSING THE QUALITY OF LIFE OF YOUNG ADULTS WITH PERINATALLY ACQUIRED HIV AT BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE.
PROTOCOL #: BBCOE-IRB-1809-08
FUNDING SOURCE:
BBCCOEIRB APPROVAL DATE: 10/10/2018
EFFECTIVE DATE: 19/12/2019
EXPIRATION DATE: 18/12/2020
IRB REVIEW TYPE: REGULAR
IRB REVIEW ACTION: RENEWAL

Dear PI:

The Botswana-Baylor COE Institutional Review Board by [FULL BOARD] has considered the research protocol submission for the project referenced above and **RENEWED.**

The RENEWAL is valid for one year from the date of the IRB approval is granted or modification required. A final report must be provided to the IRB and all records relating to the research (including signed consent forms where applicable) must be retained and available for audit for at least 3 years after research has ended.

It is the responsibility of all investigators and research staff to promptly report any serious, unexpected and related adverse events and potential unanticipated problems involving risks to subjects or others. Please do note that the researcher is still required to seek administrative or other procedural that may vary per institution.

This approval is issued under the Botswana-Baylor COE's OHRP Federalwide Assurance# 00020346.

Should you have any queries or concerns, do contact the BBCOEIRB Secretary at otshume@baylorbotswana.org.bw and cc the acting chair a jtfarirai@baylorbotswana.org.bw. Include the project titled and IRB Reference number in all correspondence with IRB.

Regards,

Dr John T. Farirai
(MBChB, Dip HIV Man, PDM, Mphil, MPH)
Chairman- Botswana-Baylor COE Institutional Review Board